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ABSTRACT

This report describes a model designed to provide family-centered, community-based coordinated services for families and their children with chronic health care needs. The model, which was implemented to serve 208 children over a 5-year period, is based on three key concepts: families should have the choice to receive services in their homes and communities instead of hospitals and/or long term care facilities; keeping children in acute care or specialty hospitals or long term care facilities is more costly; and principles of family-centered care must be incorporated into a model of coordinated services for children with chronic health care needs. Components of the model include family-centered service coordination, specialized respite care, and community development through training and consultation. Functions of the project design include: demonstration and validation of the model; training; administration and management; dissemination, replication, and impact; and evaluation and research. The report includes a description of the participants, barriers to program implementation, the accomplishments and impact of the program, dissemination activities, and charts and summaries of replication accomplishments. The results of a family satisfaction survey are also included. An appendix includes the project's management plan and an outside evaluator's review of the project. (Contains 22 references.) (Author/CR)

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PERSONALIZED PEDIATRIC COORDINATED SERVICES (PPCS)

A Family-Centered Model of Coordinated Services for Young Children with Chronic Illness and Disabilities

A grant award to the Hattie Larlham Foundation
by the U.S. Department of Education,
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The PPCS Model has validated and replicated a process for providing
Family-Centered Service Coordination
and
Specialized Respite Care Services
to children birth through eight years old with chronic illness and disabilities.

The PPCS Model also describes efforts to promote
Community Development
through training, consultation and technical assistance.

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ABSTRACT

The purpose of the Personalized Pediatric Coordinated Services Model (PPCS) is to validate and replicate a family -centered , community-based model of coordinated services for families and their children with chronic health care needs. The PPCS model was developed and implemented in the first three years of the project, the focus of the last two years was replication and dissemination.

The philosophy underlying the PPCS model is based on three key concepts: a) families should have the choice to receive services in their homes and communities instead of hospitals and/or long term care facilities, b) keeping children in acute care or specialty hospitals or long term care facilities, are more costly ways to serve these children both from a financial and emotional perspective, c) principles of family-centered care must be incorporated into a model of coordinated services for children with chronic health care needs. Components of the PPCS model include; Family-Centered Service Coordination, Specialized Respite Care, and Community Development through Training and Consultation.

Five major functions of the project design include: a) demonstration and validation of the PPCS model, b) training, c) administration and management, d) dissemination, replication, and impact, e) evaluation and research. The outcome of these functions is a validated family-centered model that provides cost effective, coordinated services for children with chronic health care needs. A total of 208 children were served over the five year period.

The impact of the project was realized in various ways: a) children with chronic health care needs and disabilities received appropriate services in their homes and community environments as selected by their families, b) families, staff and other community agencies and providers received training and support, to ensure maximum inclusion of children and their families along with appropriate transitions, c) project evaluation, dissemination, and research validated the model and defined the methods for replication, and d) the model was replicated through collaborations with two agencies in Ohio.

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PROJECT FUNCTIONS AND GOALS

Project goals and objectives are organized into five key functions. Refer to the Management Plan for years I-V (appendix) for detailed description of project activities, associated timelines and completion dates.

Function 1: Program Implementation and Validation

1. Operate a PPCS Program for families with children birth through eight having chronic health care needs.
2. Obtain referrals through Advisory Board, dissemination activities, and other community awareness activities and complete referral and intake procedures.
3. Monitor each individuals IFSP and advocate as needed.
4. Provide access to and/or services and coordination to enable families to use community services through multiple service providers.
5. Modify project procedures on basis of evaluation data.

Function 2: Training

1. Provide ongoing training for PPCS, Foundation Staff and service providers.
2. Provide education and support to families.
3. Establish university internships/field experiences for interdisciplinary personnel.
4. Provide on-site consultation for community program personnel.
5. Offer inservice training for personnel in Summit County and area agencies.
6. Recruit and train in home and out of home respite providers.

Function 3: Administration and Management

1. Determine actual program costs.
2. Establish reimbursement procedures.
3. Complete cost studies (see evaluation).
4. Administer project in accord with proposed plans and timelines.

Function 4: Dissemination, Replication, and Impact

1. Disseminate information to community agencies and other interested individuals locally, state-wide, and nationally.
2. Develop and field-test a model guide handbook and disseminate these products for adoption, in whole or in part, by other agencies in and out of Ohio.
3. Systematically replicate the model in at least 2 other sites.

Function 5: Evaluation and Research

1. Evaluate the impact of the project using formative strategies (for refinement of the approach) and summative strategies to evaluate the impact on children, families, and community service providers.
2. Evaluate the effectiveness of project management.
3. Evaluate the cost-effectiveness of the PPCS model.
4. Evaluate the impact of the project when used in replication sites.

Theoretical Framework

Appropriate supports such as respite care, early intervention and educational programming can make it very possible for families to manage the ongoing medical needs of their children at home. According to Kilpatrick, Miller, and Clarke (1988), the emotional burden that is placed on families is reduced when alternate care models that support families are easily accessible. The benefits of maintaining a child in an environment other than the traditional institutional environment are widely recognized (Hazlett, 1989; U.S. Congress, 1987; Saunders, Miller, and Cates, 1989). A home-like environment where children's care needs can be addressed in an individualized, nurturing environment by caring family members and professionals is not to be underestimated concerning the health and well-being of the ENTIRE family. In addition, or subtraction, the costs of addressing children's health care needs at home (with support) have been demonstrated to be significantly less than the costs of providing similar care in an acute care hospital (Garfunkel and Evans, 1986; Brooten et al, 1986).

Costs are incurred by families of children with chronic and special health care needs other than just monetary (Hazlett, 1989). Families report frustration in dealing with the health care system (Scharer and Dixon, 1989; Stone, 1989). Inability to obtain sufficient amounts of respite care is an issue for families especially if children are not eligible for round-the-clock nursing services (AACH, 1984; Agoste and Bradley, 1985; Hutchison, 1988; Shelton, Jeppson, and Johnson, 1987). Cost-effective alternative home care many times segregates children, parents, and siblings (Pierce, Freedman, and Reiss, 1987; Scharer and Dixon, 1989). These models also often alter family functioning and provide increased "non-therapeutic" stress (Dunst, Trivette, Davis, and Cornwell, 1988; Schlomann, 1988). They are also only available for families who can obtain waivers, have private insurance or significant financial resources, and reside in safe and reasonable environments (U.S. Congress, 1987). Furthermore, home-care systems, for the most part, are designed to address children's medical and health care needs with limited regard for developmental experiences (Pierce and Freedman, 1986; Saunders, Miller, and Cates, 1989).

Families whose infants or children are hospitalized for long periods of time frequently report feelings of loss (Scharer and Dixon, 1989). Although there is relief at being able to take a child home, high family stress levels do result from added responsibilities, restricted freedom, and uncertainty. The ideal model extends from the hospital into the community to provide support through the multiple transitions that occur with children who require special support between hospital and home (Hazel et al, 1988; Long, Katz, and Pokorni, 1989). Children from inner-city environments who are at environmental as well as biological risks for poor developmental outcomes are reported to require more support and service coordination than families who are not living in poverty (Boland, 1987; Stein and Jessop, 1985). In review, external and internal stressors for families with infants and children who require special support would include difficulty in securing or coordinating needed services, communication among family members (husband/wife; extended family), and the complications of extensive caregiving routines such as apnea monitoring, tube feeding, or respiratory procedures (Dunst, Trivette, and Cross, 1986).

In an integrated model of developmental and medical care for children with chronic illness and their families, families and nurses do act as primary care providers and other disciplines, such as early education and therapy, play consultant roles. The medical concerns of infants and children remain important, but appropriate developmental experiences gain prominence as their health improves (Hartley, White, and Yogman, 1989; Kilgo, Richard, and Noonan, 1989). Developmental experiences must be well integrated with medical care to prevent overtiring, over-burdening of children's physiological systems, and other negatively impacting factors such as increased illness or rehospitalization (Als, 1986; Hartley, White, and Yogman, 1989; Vandenberg, 1985).

In 1989, as a result of a 1987 grant to study the need for day care services for children with chronic health care needs in northeastern Ohio and the initial steps in the development of linkages among primary service providers for children with chronic illness, the Hattie Larlham Foundation and the Children's Hospital Medical Center of Akron collaboratively began to design a family-centered care system to serve children and families from summit and surrounding counties. Development of the approach has been based on the key principles of family-centered individualization and personalization in least restrictive environments, utilization of existing resources fully to include and integrate children with chronic health care needs and their families as members of their communities, ongoing evaluation, and collaborative strategies in the community to promote community "ownership" of the model. These principles are incorporated into the three main components of the currently existing PPCS model: Family-Centered Service Coordination, Specialized Respite Care Services, and Community Development.

References

Agosta, J.M. and Bradley, V.J. (Eds.) (1985). Family care for persons with developmental disabilities: A growing commitment. Cambridge, Massachusetts: Human Services Research Institute.

Als, H. (1986). Synactive model of neonatal behavioral organization: Framework for the assessment and support of the neurobehavioral development of the premature infant and his parents in the environment of the neonatal intensive care unit. In J.K. Sweeney (Ed.), The high-risk neonate: Developmental therapy perspectives (pp. 3-53). New York: The Haworth Press.

Boland, M.G. (1987). Management of the child with HIV infection: Implications for service deliver. In Report of the surgeon general's workshop on children with HIV infection and their families (pp 41-42). Washington, DC: Department of Health and Human Services.

Brooten, D., Kumar, S., Brown, L.P., Butts, P., Finkler, S.A., Bakewell-Sachs, S., Gibbons, A., Delivoria-Papadopoulos, M. (1986). A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. New England Journal of Medicine, 315, 934-939.

Dunst, C.S., Trivette, C.M., and Cross, A.H. (1986). Roles and support networks of mothers of handicapped children. In R. Fewell and P. Vadasy (Eds.), Families of handicapped children: Needs and support across the life span, pp 167-192. Austin, Texas: PRO-ED.

Dunst, C.S., Trivette, C.M., Davis, M., and Cornwell, J. (1988). Enabling and empowering families of children with health impairments. Children's Health Care, 17 (2), 71-81.

Garfunkel, J.M. and Evans, H.E. (Eds.) (1986). Hospital care for children and youth. Elk Grove Village, Illinois: American Academy of Pediatrics.

Hartley, M., White, C., and Yogman, M.W. (1989). The challenge of providing quality group child care for infants and young children with special needs. Infants and Young Children, 2 (2), 1-10.

Hazel, R., Barber, P.A., Roberts, S., Behr, S.K., Helmstetter, E., and Guess, D. (1988). A community approach to an integrated service system for children with special needs. Baltimore: Paul H. Brookes.

Hazlett, D.E. (1989). A study of pediatric home ventilator management: Medical, psychosocial, and financial aspects. Journal of Pediatric Nursing, 4 (4), 284-294.

Hutchinson, L. (1988). Technology dependent children: How much does society really care? NACHRI Newsletter, XIX (2).

Kilgo, J.L., Richard, N. and Noonan, M.J. (1989). Teaming for the future: Integrating transition planning with early intervention services for young children with special needs and their families. Infants and Young Children, 2 (2), 37-48.

Kilpatrick, K.E., Miller, M.K., and Clarke, L.L. (1988)., An evaluation of the relative economic and psychological stress on families of children enrolled in the prescribed pediatric extended care center and those of children cared for in other settings. Gainesville, Florida: MAPS.

Long, T., Katz, K., and Pekorni (1989). Developmental intervention with the chronically ill infant. Infants and young children, 1 (4), 78-88.

Pierce, P.M., Freedman, S.A., and Reiss, J.G. (1987). Prescribed pediatric extended care (PPEC): A new link in the continuum. Children's Health Care, 16 (1), 55-59.

Saunders, R.B., Miller, B.B., and Cates, K.M. (1989). Pediatric family care: An interdisciplinary team approach. Children's Health Care, 18 (1), 43-47.

Scharer, K. and Dixon, D.M. (1989). Managing chronic illness: Parents with a ventilator-dependent child. Journal of Pediatric Nursing, 4 (4), 236-247.

Schlomann, P. (1988). Developmental gaps of children with a chronic condition and their impact on the family. Journal of Pediatric Nursing, 3 (3), 180-187.

Shelton, T.L., Jeppson, E.S., and Johnson, B.H. (1987). Family-centered care for children with special health care needs (second edition). Washington, DC: Association for the Care of Children's Health.

Stein, R.E.K. and Jessop, D.J. (1985). Delivery of care to inner-city children with chronic conditions. In N. Hobbs and J.M. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco: Jossey-Bass.

Stone, D. (1989). A parent speaks: Professional perceptions of parental adaptation to a child with special needs. Children's Health Care, 18 (3), 174-177.

Vanden Berg, K.A. (1985). Revising the traditional model: An individualized approach to developmental interventions in the intensive care nursery. Neonatal Network, April.

PPCS Model Description

The PPCS model consist of three main components

- Family-Centered Service Coordination
- Specialized Respite Care Services
- Community Development Through Training, Team Consultation, and Technical Assistance

Family-Centered Service Coordination

Family-Centered Service Coordination is an active process of: (1) determining with a family their priorities, resources and concerns; (2) assisting the family to locate and coordinate the services, equipment, funding, therapies, educational programs or respite services to support the entire family and their child with chronic health care needs and mental retardation or disabilities; and, (3) monitoring of the quality of services provided to families and providers trained.

Specialized Respite Care Services

Specialized Respite Care Services consists of: (1) the recruitment and training of specialized respite care providers; (2) matching trained providers with families; and, (3) monitoring the quality of respite care services in the home. Specialized Respite Care Providers are extensively trained through completion of the PPCS Respite Training Course (40 hours), two hours of Hands-On-Training in the family's home with the RN Assessor present, and four hours supervised time in the family's home with the family present. Family preferences and individual care needs are determined during a home visit to facilitate a successful match between the family and the provider.

Community Development Through Training, Team Consultation, and Technical Assistance

The PPCS project offers training, team consultation and technical assistance to agencies and providers working with young children to ensure responsive community development of programs and activities which promote the inclusion of all children, including those with chronic health care needs.

Description of PPCS Participants

PPCS provides services to families with children birth through eight years of age who have mental retardation, developmental disabilities or chronic health concerns. Since October of 1991, a total of 208 individuals have been served through PPCS. The following table reflects the number of individuals served through PPCS during each year of the project.

Year	Number Served
1991	27
1992	59
1993	81
1994	89
1995	122
1996	100

The distribution of services provided to the 208 individuals receiving PPCS services follows. The description reflects the service the individual currently receives or was receiving when the case was closed. It is common for families involved with PPCS to initially request respite yet soon after receiving respite they also begin to utilize service coordination services. Once services are coordinated and family concerns are addressed then the family will return to receiving respite services only.

Service Coordination Only	95
Respite Only	91
Service Coordination & Respite	22

The 208 individuals served came from 14 counties in the state of Ohio, 111 of them were between the ages of Birth and 2 years when they started with the program, 55 were between the ages of 3 and 5 years, and 42 were between the ages of 6 and 8 years. 81 of these individuals were female and 127 were male.

Analysis of data collected was stratified by age categories as well as the level of care required by the individual. Level of care I includes individuals with tracheotomy, oxygen therapy, aerosol treatments, nutritional supports (ng/g-tube), postural drainage, IV therapy, frequent suctioning, or who require a ventilator. Level of care II includes individuals who have on-going medication usage, on-going therapy needs, seizures or apnea. The distribution of individuals served through PPCS by level of care follows.

Level of Care I	97
Level of Care II	111
Total	208

Of the 208 individuals served since the beginning of the project: 77 currently receive PPCS services, 83 individual cases were closed due to no longer needing or wanting services, an additional 33 individual cases were closed for a variety of reasons, mostly affiliated with funding issues, and 15 individuals who received services through PPCS expired.

The following table reflects the more common diagnosis of individuals served by PPCS.

DIAGNOSIS	Frequency
ADHD	2
Arthrogryposis	2
Asthma	3
BPD	35

CMV	4
Congenital Heart Defect	3
Cerebral Palsy	44
Developmental Delay	13
Down Syndrome	2
Failure To Thrive	3
Gastro-esophageal Reflux	7
Hydrocephaly	10
Hypotonia	3
Microcephaly	6
Mental Retardation	5
Prematurity	28
Retinopathy of Prematurity	4
Seizure Disorder	47
Shaken Baby Syndrome	3
Spina Bifida	2
Trisomy 18	2
Werdnig Hoffman Disease	2

In order to describe the financial situation of families receiving PPCS services an attempt was made to obtain the income level of families receiving services. What was collected follows.

Income Range	
$ 0 - $ 11,500	2
$ 11,501 - $ 20,500	7
$ 20,501 - $ 27,258	6
Less than $ 27,258	47
$ 27,259 - $ 37,759	13
$ 37,760 - $ 48,260	13
$ 48,261 - $ 62,261	1
$ 62,262 - $ 79,762	1
$ 79,763 - over	1

117 families chose to not report their family income

Families served by PPCS utilize a variety of Federal and Ohio state sources of reimbursement in order to fund necessary services including: Medicaid Home and Community Based Waivers, Family Resource Programs, Community Alternative Funding System (C.A.F.S.), Individual County Supported Living Dollars, and State Grants from the Ohio Department of Mental Retardation/Developmental Disabilities and the Ohio Department of Health, Bureau of Early Intervention. Local philanthropic organizations also donate respite funding. Services provided by PPCS were not covered by the family's private insurance. The programs may not be mutually exclusive, depending on state and county regulations. Families continually change and their funding situations change as well. Children outgrow eligibility, age requirements, medical conditions worsen or improve, or families move outside of eligible geographic locations. Therefore it is often necessary for families to have more than one funding source at a time or to change funding sources over time.

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Barriers At The Hattie Larlham Foundation And Adaptations Made From The Original Grant Proposal.

The following recounts the barriers faced during model development and replication as well as variations to the model since the original grant proposal. All of the adaptations were approved by the grant officer when they were made and the grant officer has been informed of mentioned barriers as they arose.

The original grant proposal included the use of a comparison group to assist in determining model impact. The comparison group was established in a geographical area outside of our standard service area. After meeting with families in this group to collect information the comparison group was abandoned. Ethically as a service organization we could not identify family needs and then not find means of satisfying those needs.

The proposed model was comprised of five components (a) referral and intake, (b) individual family service plan (IFSP), (c) services for infants and young children and families, (d) case management (service coordination) including the coordination of transitions; and (e) training of service providers (including early intervention, daycare, respite care). The first adaptation to this proposed model came early on in the grant. IFSP's were either already written by county departments of MR/DD or were the responsibility of County Board of MR/DD staff. The PPCS model did not deem it appropriate to create another plan for individuals served by the project. Rather it became a PPCS goal to assure that each individual had an IFSP, that the plan was appropriately monitored and followed, and PPCS staff became active advocates at plan meetings were necessary.

The second adaptation to the proposed model is a categorical one significant only in terms of presentation of the model. The original five components were restructured into three components; Family-Centered Service Coordination, Specialized Respite Care Services, and Community Development.

Adaptations were also made to the proposed evaluation/research plan. The amount and type of information collected from project families was simplified as a direct result of feedback from project families. Families found the paperwork to be too cumbersome, one family stated that "the time it took filling out papers used up all her respite hours". Only minimal data was returned by families in the first three years of the project. Changes to the evaluation plan were made after the site review at the end of the third grant year. These modifications significantly impacted data collection. Not only were measures stream-lined but the project evaluation plan became the evaluation plan for the department. This assured some data collection and greatly improved return rates of family evaluation forms.

Another barrier PPCS had to overcome was a high rate of PPCS management staff turn over. Each time staff changed the focus and direction of the project was impacted.

A large obstacle to PPCS model development was regulatory and funding barriers. Locating funding to pay for PPCS service was a constant focus complicated by the fact that their was not state or private funding to cover the costs of services required to assure safe and appropriate care. Specifically there were not funds for reimbursement of assessments done by registered nurses, training of respite providers, or supervisory visits. The funding barrier became a significant complicating factor in trying to secure replication sites because the model requires assessments, extensive training of providers, and supervisory visits and potential replication sites could not afford the additional cost which would be incurred.

Also, in terms of regulatory obstacles PPCS had to overcome the barrier of what the state would pay for a provider to do compared to what the state allowed the provider to do. For example: the state would only pay for a non licensed provider to provide care but the care required by the individual needs a licensed provider. This is an obstacle faced by the main site as well as replication sites.

Barriers in relation to replication sites

The original grant proposed that the PPCS model would be replicated in five sites. Due to geographical limitations, model design, and staff size the replication site requirement was reduced to two to three sites at the suggestion of grant reviewers at the end of the third year of the project. Securing replication sites was difficult for

reasons previously mentioned, specifically funding issues and regulatory barriers. Beginning in 1994, eighteen agencies/collaborative groups were contacted regarding possibly replicating the PPCS model. These 18 attempts spanned three states and resulted in two replication sites.

Once the two replication sites were identified the project had to deal with competitiveness agencies most significantly impacting grant time lines and data sharing, complicated by replication staff turn over, redeployment and an employee strike at one of the sites. These barriers also significantly impacted data collection. Lack of quantitative data from replication sites impaired PPCS's ability to evaluate the effectiveness and impact of the model. Replication sites prioritize agency activities and already established information collection over replication data collection. There was no process in place to assure data collection at replication sites this would have been addressed through a more specific replication contract.

PPCS Impacts

In October of 1991, the Hattie Larlham Foundation began the development of the Personalized Pediatric Coordinated Services model. This model encompasses Family-Centered Service Coordination, Specialized Respite Care, and Community Development.

Through implementation, replication and dissemination efforts, PPCS has had a positive impact on families and their children with chronic health care needs as well as the agencies serving these children and their communities.

The Hattie Larlham Foundation has provided service coordination and/or specialized respite services to 208 families and over 200 respite care providers were trained through the specialized respite care training course. The PPCS staff provided both formal and informal inservices and workshops to families, providers, and agencies encompassing issues pertinent to the population of people with disabilities and children with chronic health care needs. Dissemination activities of the project took information regarding how to serve these children to a variety of people spanning different backgrounds, education, and geographic locations. Replication efforts gave other agencies the information necessary to position themselves to provide these services. PPCS impacted the greater community through collaboratively sponsoring a state-wide conference. This conference was attended by families and professionals and allowed for dissemination of PPCS information as well as provided workshops on various topics; including: estate planning, outcomes for people, and adapted toys for children with disabilities. Overall participant attendance at the conference along with estimated attendance at formal inservice/workshops totaled over 300, this did not include families and providers trained or those impacted through replication efforts.

At the Medina replication site PPCS efforts directly impacted staff in three areas; those working in early intervention, case management, and respite care services. Medina received technical assistance relating to the provision of service coordination, they modified their respite training course, and formalized some assessment and evaluation processes. Through these efforts more than 50 families were indirectly impacted and more than 40 respite providers were trained through the Medina respite training course which is a replica of the PPCS Specialized Respite Training Course.

Through replication efforts at Health Hill Hospital for Children, PPCS directly impacted the staff and protocol of their Specialized Family Care Program. This resulted in a foster and respite provider training course which is modeled after the PPCS Specialized Respite Training Course. Health Hill's first training class was attended by 16 individuals. PPCS efforts will indirectly impact more families at Health Hill as their program continues to train foster parents and providers and as Health Hill implements their evaluation plan which is a replica of the PPCS model evaluation.

Dissemination of this model has been accomplished through a variety of activities. PPCS staff have presented at national, regional, and state conferences. Inservices have been presented to numerous agencies. PPCS information was given to individuals from multiple agencies in three states for the purpose of recruiting replication sites. Dissemination extended through the publishing of a PPCS related article in the Journal of Developmental and Physical Disabilities. Two other articles are ready to be submitted for publication.

The PPCS project has produced the following products to assist others in the field to understand and use the PPCS model: the PPCS Fact Sheet, the PPCS Brochure, the PPCS Model Handbook, the PPCS Parent Handbook, and the PPCS Video.

PPCS Accomplishments - HLF

Function 1: Program Implementation and Validation

The Community Services Department of the Hattie Larlham Foundation has designed and implemented the PPCS model of family-centered coordinated services for families and their children between the ages of Birth - 8 years, who have chronic health care needs and disabilities. The PPCS Model includes the provision of family-centered service coordination and specialized respite care services to this population as well as offering community development through team consultation and training to professionals and service providers in the communities where these families live.

Over 200 individuals have received PPCS services since October of 1991. These families have been provided access to services and service coordination which enables them to use community services through multiple service providers. PPCS staff have been active in these individuals IFSP's when appropriate and PPCS model procedures have been modified on an ongoing basis in response to results of evaluation data from these families.

Function 2: Training

The PPCS project has recruited and trained over 200 providers since October of 1991. These providers receive initial training as well as opportunity for inservice trainings on an ongoing basis while they work with the program. Families receiving PPCS services have access to PPCS staff for support and as a resource.

Inservice opportunities have been offered to respite providers, other community agencies and HLF staff on a variety of topics. PPCS has also provided field experience to college students in the fields of nursing, early education, special education, and family studies.

Function 3: Administration and Management

PPCS has been administered in accordance with proposed plans and timelines. PPCS has successfully secured funding to provide PPCS services to families. Reimbursement procedures have been implemented and are functional. The project has gone to great lengths to describe the cost for PPCS services in order to provide services in numerous counties, to individuals with varying medical needs and diverse family requests. The cost for PPCS services are very individualized and negotiated with each funding source almost on a case by case basis. Cost studies have been attempted and available data reported.

Function 4: Dissemination, Replication, and Impact

Information about the PPCS model has been disseminated through poster presentations and break out session presentations at local, statewide and national conferences. Information has also been disseminated to community agencies and colleges. The project has produced a model handbook designed to assist others in providing family-centered service coordination and specialized respite care services to children with chronic health care needs and disabilities. PPCS project products have been on display at each conference where PPCS was presented and products are available by contacting the Hattie Larlham Foundation. The PPCS model has been replicated in two other sites and positive impacts have resulted from these endeavors.

Function 5: Evaluation and Research

An evaluation plan, utilizing surveys and interviews, was implemented and refined as necessary in order to evaluate the impact of PPCS services on children, families, and community service providers. The project contracted with an outside evaluator during the fifth year of the project to assist in evaluating the impact of PPCS in replication sites.

Three articles have been produced using findings from the project. One article has been published and will be presented at the 3rd Annual Pediatric Conference in Akron. Two other articles are being submitted for publication.

PPCS Products and Dissemination Activities

Products:

PPCS Brochure
PPCS Fact Sheet
PPCS Model Policy Statement
PPCS Parent Handbook
PPCS Model Handbook
PPCS Respite Training Manual
PPCS Model Video

* All products are available through contacting the Hattie Larlham Foundation, Community Services Department at 9772 Diagonal Road Box 1200, Mantua, Ohio 44255-1200.

Dissemination Activities

2/10/93	Presentation at Summit Co. MR/DD
3/16/93	Presentation at Ohio Early Childhood Conference in Columbus
4/20/93	Presentation at Summit Co. Early Intervention Conference
4/29/93	Presentation at Regional Prenatal Conference
7/13/93	Poster Presentation at Regional Head Start Conference in Birmingham
10/7/93	Presentation at Division of Early Childhood Conference (Regional)
11/5/93	Presentation to Northeast Faculty Institute (Regional)
11/19/93	Presentation at Stark County Collaborative Group
11/16/93	Presentation to Child/Adolescent Nurse Practitioner Students
8/94	Presentation at Southeastern Regional Head Start/Early Childhood Conference
8/94	Poster Presentation at Illinois Early Childhood Education Conference
12/94	Poster Presentation at Annual EEPCD Projects Meeting
7/95	Presentation at Cuyahoga Early Intervention County Collaborative Group
8/95	Presentation at United Disabilities Services in Akron
10/2/95	Presentation at PAR Conference in Columbus
10/19/95	Poster Presentation at Caring for Infants and Toddlers with Disabilities: New Roles for Physicians in Cleveland
10/23/95	Poster Presentation at Caring for Infants and Toddlers with Disabilities: New Roles for Physicians in Dayton
10/26/95	Poster Presentation at Children and Chronic Illness, Second Annual Nursing Conference in Akron
11/2/95	Presentation at Family Vision '95 in Kent
11/15/95	Poster Presentation at Seventh Annual National Conference of Respite and Crisis Care Programs in Washington, D.C.
12/6/95	Poster Presentation at Annual EEPCD Projects Meeting in Washington, D.C.
6/4/96	Presentation at Family Vision '96 in Columbus

Publications and articles submitted for publication:

Schultz, G.S. (1996) Taxonomy of rights: A proposed classification system of rights for individuals with mental retardation or developmental disabilities. Journal of Developmental and Physical Disabilities, 8 (3), 275-285.

Schultz, G.S. (1996). The taxonomy of rights and educational objective attainment

Schultz, G.S. (1996). In my own backyard: A Review of Personalized Home Care Models Vs. Institutionalization.

PPCS Replication Accomplishments - Medina County Board of MR/DD

The Medina County Board of MR/DD agreed to replicate the Family-Centered Service Coordination component, the Specialized Respite Care Services component and the Community Development component of the PPCS Model in June 1994.

In relation to the Family-Centered Service Coordination Component the following accomplishments were noted at the Medina site. There was an increased awareness of the differences between case management services and family-centered service coordination. Replication staff demonstrated increased awareness, knowledge and skills in translating the principles of family-centered care and service coordination into daily roles and responsibilities. Replication staff increased utilization of the team approach to providing service coordination.

In relation to the Specialized Respite Care Component the following accomplishments were made at the Medina site. Medina adopted the PPCS Specialized Respite Training Manual with minor adaptations to account for difference in population served. Recruitment activities were increased and more training opportunities were offered. A standard process for Hands-On-Training with the respite providers was adopted with minor adaptation to accommodate population and staffing limitations. There was an increased awareness of the follow-up needs of respite providers and the regulations which govern the provision of respite care services.

In relation to the Community Development Component the Medina site facilitated community development and awareness activities through presentations at conferences and continued involvement on community planning boards. The Medina site also facilitated smoother transitions for families from early intervention services to preschool services through conducting training sessions and providing technical assistance in the development of transition policies and procedures.

Throughout the Medina site there was an enhancement of their information collection system which supported program evaluation and quality assurance.

Barriers to Replication - Medina County Board of MR/DD

A significant barrier to replication activities in Medina stemmed from a high rate of staff turn over and redistribution of staff through-out the agency. This was complicated by a ten week strike which put replication activities on hold and a location move of the department which resulted in lost materials and data.

Another barrier was the differences in statutory and fiscal regulations as well as accrediting bodies. This impacted the forms used for reporting and service delivery requirements.

Replication of the Family-Centered Service Coordination component at the Medina site was complicated by the fact that service coordination in Medina is accomplished collaboratively between three departments. Service coordination could be done by an early interventionist, a case manager, or by the residential department. Trying to replicate the service coordination model component simultaneously in three departments made it difficult to maintain the integrity of the model.

MEDINA CO. BOARD OF MR/DD
PPCS REPLICATION

***** Medina Board of MR/DD was on strike for 10 weeks beginning 4/6/96

Objective/Activity	Plan	Staff	Where & When	Notes	Status
Needs Assessment			7/94		Complete
Advisory Board	Medina is using the Medina Co. MR/DD Board of Directors as their advisory board. They meet monthly.	Rich Willse	Monthly 1/95 - 9/96		Complete
Recruitment	1. Meet to discuss recruitment techniques & ideas 2. Discuss recruitment 3. Review most effective recruitment activities.	1. Margo Gibson, Rich Willse 2. Margo Gibson, Rich Willse 3. Carey Anderson, Rich Willse	1. 1/11/95 Medina 2. 6/23/95 Medina 3. 3/8/96 Medina		1. Complete 2. Complete 3. Complete
PPCS process & forms	1. Review PPCS Service Coordination process and forms. 2. Review PPCS Respite process & forms.	1. Margo Gibson, Ken Miller, Stacey McFarland - Donna Daley, Karen 2. Margo Gibson, Rich Willse, Toby	1. 2/8/95 Medina 2. 2/8/95 Medina		1. Complete 2. Complete

Service Coordination policy & procedures & technical assistance	1. Beginning discussions with Medina staff	1. Margo Gibson, Donna Daley	1. 1/26/95 Medina		1. Complete
	2. Accompany Medina staff on a Home Visit to provide technical assistance.	2. Margo Gibson, Donna Daley	2. 7/14/95		2. Complete
	3. Review individual cases with Medina staff for the purpose of technical assistance	3. Margo Gibson, Karen Tanski	3. 2/9/96		3. Complete
	4. Process/protocol for Service Coordination	4. Carey Anderson, Rich Willse, Donna Daley, Karen Tanski	4. 3/20/95	4. Documented notes on process no formal written process.	4. Documented notes reviewed and approved by Rich W. 7/30/96

Respite policy & procedures & technical assistance	1. Review forms training and recruitment procedures.	1. Margo Gibson, Rich Willse	1. 6/23/95		1. Complete
	2. Review training & curriculum	2. Margo Gibson, Rich Willse, Robin Dickson, Marc (RN)	2. 10/10/95		2. Complete
	3. Discuss need to develop hands on training checklist and respite procedures	3. Margo Gibson, Rich Willse	3. 2/13/96	3. Need copy of hands-on-training checklist.	3. Received 9/3/96
	4. Process/protocol for the following areas: Recruitment Interviewing Training Intake/Referral Assessment Matching Hands-on-training Supervisory visits Evaluation	4. Carey Anderson, Rich Willse	4. 3/8/96 4/19/96	4. Informally these points were gone over at the 3/8/96 meeting. They have been documented in the Medina book. Written processes have not been done as of yet. Continued task on 4/19/96	4. Documented notes of Medina Process were reviewed and approved by Rich W. 7/30/96

Funding/Staff time	1. Have Medina staff fill out a PPCS billable time sheet for 1 month.	1. Margo Gibson, Karen Tanski	1. July 1995		1. Complete
Defining Population	Establish criteria to define individuals to be tracked, and estimate number of individuals.	Margo Gibson, Donna Daley	2/13/95		Complete
Comparing PPCS & MR/DD process & forms	1. Review MR/DD case management forms & Community Services Billing & non billable sheet.	1. Margo Gibson, Ken Miller	1. 2/17/95		1. Complete
Quality Assurance	1. Meet with John Stephanic to discuss current Medina quality assurance measures. 2. Quality assurance is done through CARF, the MR/DD board of directors and the Housing advisory board.	1. John Stephanic, Margo Gibson 2. John Stephanic, Rich Willse	1. 4/21/95 2. On-going		1. Complete 2. On-going

Respite Training	1. Observe training's.	1. Margo Gibson	1. 1/23 -1/25/95; 3/1 - 3/3/95; 3/27-3/29/95 6/1-6/2/95 7/26-7/28/95 10/4-10/5/95 10/31-11/1/95		1. Complete 2. Complete
	2. Provide feedback to Medina training staff regarding training.	2. Margo Gibson	2. 1/26/95; 3/29/95 8/2/95 10/10/95		
	3. Planning meetings prior to training's.	3. Margo Gibson, Rich Willse	3. 1/11/95 2/9/95 5/31/95 10/1/95 1/30/96 2/13/96		3. Complete
Replication Meetings	1. Meet to review, address issues and progress	1. Margo Gibson, Rich Willse	1. 6/23/95 9/27/95 1/30/96 2/9/96 3/8/96 4/19/96	** 3/8/96 meeting with Rich was a complete review of replication activities. Notes are documented in Medina book.	1. Complete
	2. Meet to update replication activities	2. Carey Anderson, Robin Dickson, Stacey McFarland, Karen Tanski	2. 1/5/96		2. Complete

Program Evaluation	1. Train Medina staff to score & interpret evaluation measures.	1. Margo Gibson, Carey Anderson, Donna Daley	1. 3/20/95		1. Complete
	2. Provide John Stephanic with a copy of the Project Dakota Survey - PSS.	2. Margo Gibson	2. 4/6/95		2. Complete
	3. Provide John Stephanic with validation information for Project Dakota Survey - PSS	3. Margo Gibson	3. 4/13/95		3. Complete
	4. Data training meeting	4. Carey Anderson, Margo Gibson,Robin Dickson, Rich Willse, Donna Daley, Karen Tanski, Stacey McFarland, Allen	4. 10/20/95 11/17/95		4. Complete
	5. Set up provider D-Base computer system for Medina.	5. Carey Anderson, Robin Dickson	5. 12/21/95 1/5/96		5. Complete
	6. Adapt information and consent form and procedure for recruiting families to collect data from.	6. Carey Anderson, Robin Dickson, Stacey McFarland, Karen Tanski	6. 1/5/96	6. Robin will send info & consent to all eligible families on 1/8/96 to be returned by 1/22/96. Approx. 26 eligible families. * 4 replies by 1/26 - 2 YES 2 NO (too busy)	6. Complete
	7. Resend info & consent	7. Robin Dickson	7. 2/8/96	7. Sent 2/8/96 return by 2/22/96. * 3 replies by 4/19 - 2 YES 1 NO	7. Complete

	8. Evaluation updates with staff	8. Carey Anderson, Donna Daley, Karen Tanski	8. 2/28/96 2/28/96	8. Donna asked 8 families none of which would participate. Their reasons were *too much paperwork*no time*working parents.	8. Complete
	9. Staff interviews	9. Carey Anderson, Karen Tanski, Donna Daley	9. 3/8/96		9. Complete
	10. Adapting/editing of PPCS evaluation forms.	10. Carey Anderson, Rich Willse	10. 4/19/96 5/21/96	10. changes to Provider Training Satisfaction Survey - Survey to be sent to all individuals trained in 1995.	10. Complete
	11. Technical assistance with computer systems for Medina	11. Carey Anderson, Allen	11. 11/17/95		11. Complete
	12. A. Respite Satisfaction Survey mailed in 5/95	12. A. Rich Willse	12. A. 5/95	12. A. Survey was sent but surveys received were lost during office moves in Medina.	12. A. Complete
	12. B. Respite Satisfaction Survey mailed in May 1996	12. B. Rich Willse	12. B. 5/96	12. B. Data was received and analyzed.	12. B. Complete
	13. Provider Training Satisfaction Survey adapted and sent to all providers trained in 1995 who are still providing.	13. Rich Willse, Carey Anderson	13. 3/8/96	13. 3/8/96 4/19/96 5/3/96 5/21/96	13. After many discussions for sending this and adaptation of the form made - it still was not sent to providers.
31	14. Demographics - collected from families receiving respite from a provider trained in 1995.	14. Carey Anderson, Rich Willse	14. 3/8/96	14. Discussed on 3/8/96 Data collected 8/21/96	14. Complete 32

Presentations/Dissemination/ Community Development	1. Presentation at PAR conference with Medina staff and a Medina family.	1. Margo Gibson, Rich Willse, 1 Medina family	1. 10/2/95		1. Complete
Conference- Collaboration for Family Vision '96	1. Begin discussions regarding conference.	1. Carey Anderson, Rich Willse	1. 3/8/96		1. Complete
	2. Conference breakout session topic exploration & development	2. Carey Anderson, Rich Willse	2. 3/15/96 3/27/96 4/2/96		2. Complete
	3. Conference moderator paragraph	3. Carey Anderson, Rich Willse	3. 4/19/96		3. Complete
	4. Breakout session presented.	4. Rich Willse	4. 6/4/96		4. Complete
Community Development - Process for centralized intake through-out Medina County.	1. Facilitate collaborating meetings between Medina Co. Board of MR/DD and Medina Co. Board of Health.	1. Carey Anderson, Margo Gibson	1. 9/30/94 11/4/94		1. Complete
Community Development - Provide technical assistance for Community satisfaction & knowledge assessment.	1. Assist with setting up a computer data base for the results of the Community assessment. survey.	1. Margo Gibson, Carey Anderson, Sharon Biggins	1. 6/95		1. Complete
	2. Assist in evaluating/ analyzing the results of the community assessment survey.	2. Margo Gibson., Carey Anderson, Sharon Biggins	2. 6/95 7/95		2. Complete

PPCS Replication Accomplishments - Health Hill Hospital for Children

The Specialized Family Care Program of Health Hill Hospital for Children initially contracted to replicate the training portion of the PPCS model, specifically the PPCS respite training curriculum. Although this initially was the focus of replication Health Hill chose to replicate other parts of the PPCS Specialized Respite Care Services model as well as making advances in the area of Community Development.

Health Hill created a comprehensive training curriculum based on the PPCS model amending sections of their previous training's relevant to their population. Their training curriculum simultaneously trains foster parents and respite providers ensuring a common knowledge base, networking among foster parents and providers, and fostering relationships between them. This system of training also gives potential foster families, who may be unsure if they want to foster, an opportunity to first provide respite without the long term commitment of fostering. Another benefit of simultaneously training foster parents and respite providers is that it encourages acceptance of the concept that the respite provider will follow the child. Therefore if the child moves to another foster family or returns to it's birth family or to an adopted family the respite provider will be a constant and provide respite in those areas as well. There is also opportunity for a foster family to provide respite for the birth family once reunification has occurred.

Health Hill training curriculum was successfully used with a training class. A variety of instructors taught within their related areas of expertise. The use of audio-visuals, handouts, hands on training, and group discussion emulated the PPCS model and was well received. Provider satisfaction with training was evaluated after each section of the course. Health Hill staff reported that they felt that the foster parents trained with the providers recognize the importance of respite and the need for networking among foster parents and providers. Health Hill made adjustments to their training curriculum/training class based on provider and PPCS staff feedback and their second training was scheduled to begin at the end of September 1996.

Health Hill put forth additional effort to formalize a process of providing specialized respite care services to the foster families they serve. Health Hill has networked with outside agencies and community groups to assist them with the recruitment of respite providers. The Hospital has exhibited increased knowledge of the regulations which govern the provision of respite services and have explored other funding sources which resulted in extension of current funding sources and an award ensuring future funds for the next three years for respite services. Receiving these funds further encouraged Health Hill to formalize the process of providing specialized respite care services. This resulted in a detailed evaluation plan which included adoption of measures used by the PPCS model. Prior to this award, replication of the PPCS model and designing a respite program was an added responsibility for the hospital staff. Health Hill will now be able to organize their staff so that there will be an individual responsible for coordinating respite care services.

Health Hill also made strides in the area of community development. Not only did they network with community agencies to better their services and locate funding, they also assisted with a state wide conference sponsored by the Hattie Larlham Foundation, PPCS. This assisted in disseminating information regarding PPCS and replication of the model. Replication activities at Health Hill has assisted in opening communication and collaborative efforts between Health Hill and the Hattie Larlham Foundation. As a result of replication efforts their are discussions of replicating the training/respite program of the Specialized Family Care Program, to provide respite to other families served through Health Hill Hospital not just foster families.

Barriers to Replication - Health Hill Hospital for Children

Replication at the Specialized Family Care Program of Health Hill Hospital for Children began at the end of the fourth year of the PPCS grant. This was first complicated by the fact that Health Hill Hospital for Children and the Hattie Larlham Foundation are competitors in providing health care services for this population. Being competitors significantly impeded progress in the initial stages of replication discussion and contract negotiations.

With preliminary stages taking considerably more time than planned, limited time remained to complete replication activities. This was both an advantage and a disadvantage. Due to time constraints Health Hill probably moved faster than they would have to complete one training by the end of grant. The disadvantage is that by starting late, time was only allowed for one training class. Health Hill's second training was beginning a week before the end of the grant so HLF could not observe whether discussed suggestions and recommendations were acted upon. These barriers resulted in a lack of data sharing and data collection which significantly impaired evaluation of replication impacts.

Additionally, it took a conscience effort on the sides of both Health Hill Hospital for Children and the Hattie Larlham Foundation PPCS staff to retain the integrity of the PPCS model while creating a curriculum that trained both respite providers and foster families. This was a barrier in terms of the time necessary to put together training course materials. Although this put us behind timelines, the efforts of replication and PPCS staff resulted in a comprehensive training curriculum which retained the integrity of the PPCS model and trained foster families.

HEALTH HILL HOSPITAL FOR CHILDREN
PPCS REPLICATION

Objective/Activity	Plan	Staff	Where & When	Notes	Status
Needs Assessment			July 1995		Complete
Review Curriculum.	Compare HH's current curriculum with HLF/PPCS respite curriculum.	Ronna Johnson, Gary Schultz, Carey Anderson	Sept. 29, 1995 at 9:30 at HLF		Complete
Funding issues	HLF & HH staff meet to discuss funding issues, ideas & options.	Patty Heisser, Rita Enlow, Paulie Velotta, Carey Anderson, Margo Gibson	October 3, 1995 at 3:00 at HH		Complete
Recruitment	Meeting between HH recruiter and HLF Community Services Recruiter to brainstorm recruiting techniques and ideas.	Rich Livingston, Carol Falender (HH recruiter)	September 29, 1995		Complete
HLF Curriculum	Provide a copy of course curriculum to HH staff after Replication Contract has been signed.	Carey Anderson	September 9, 1995		Complete

Define HH - SFCP population	Look at past demographic information of children served through HH foster services.	Ronna Johnson, Carey Anderson, Rita Enlow	September 20, 1995	Some demographic information was entered into the computer. But this process was put on hold. There was discussion of future data collection methods and out of a desire not to duplicate work this method was discontinued.	Addressed later...
Assess computer capabilities in terms of data collection & evaluation	Meet with HH's computer specialist to discuss systems which are already in place.	Kristi Lines (HH), Carey Anderson	September 20, 1995	Discussed computer programs available as well as access to the SPSS program.	Complete
Establish an Advisory Board	Rita Enlow will be looking into existing advisory boards within HH and ideas for new ones.	Rita Enlow	ASAP	- Rita has had discussions with other HH staff regarding this. One idea is to create an advisory board for their department. This would meet the advisory board requirement. - Through HH application & receiving a grant from the Cleveland Foundation HH SFCP staff collaborate regularly with the Cuyahoga Board of MR/DD, the Cuyahoga Co. Dept. of Children & Family Services. A respite provider is active in these collaboration. This will serve as their advisory board.	Complete

Program Evaluation	1. Introduce & discuss PPCS evaluation tools and measures. Assess any evaluation tools in place at HH and begin discussion of evaluation plan for HH-PPCS replication.	1. Rita Enlow, Ronna Johnson, Carey Anderson, Jeff Land, Margo Gibson	1. October 11, 1995 at HH	1. Computer programs were discussed specific tools were not discussed at this time.	1. Ongoing
	2. Review of evaluation measures. Gave HH copies of all PPCS evaluation tools. Mailed HH a draft copy of PPCS Model handbook. Discussion for need for staff interviews to look at qualitative impacts of replication.	2. Rita Enlow, Jeff Land, Carey Anderson	2. 3/8/96		2. Complete
	3. Review of evaluation tools & measures especially in regards to PPCS evaluation & the evaluation plan for HH grant application to the Cleveland Foundation.	3.Rita Enlow, Carey Anderson	3. 6/5/96		3. Complete
	4. Copy of evaluation plan used by HH.	4. Rita Enlow	4. Received in mail on 6/24/96		4. Complete
	5. Copy of evaluation forms adapted from PPCS forms.	5. Rita Enlow	5. 8/96		5. Received 9/17/96

	6. Data	6. Rita Enlow	6. 10/96	6. - PPCS will receive a copy of all returned data prior to 9/30/96. - There will be no monthly data collected until Oct. 1996 when the Cleveland Foundation Grant begins.	6. Received Satisfaction data from HH Respite Training. Data entered and analyzed.

Observation of HLF/PPCS Respite Training Course.	HH staff member to observe PPCS respite training.	Ronna Johnson	September - October 1995	Ronna was given the training schedule for October as well as opportunity to review tapes of PPCS instructor teaching a respite training. Ronna did not attend PPCS training because she had attended one previously as a participant .	Complete
Replication Meeting	Meeting between HH and HLF staff to address curriculum and replication questions & issues as well as to address data collection and evaluation issues.	Jeff Land, Rita Enlow, Carey Anderson, Margo Gibson	October 11, 1995 at 10:00 at HH		Complete
HH - SFCP Training Manual	1. Creation of SFCP training manual incorporating PPCS training manual.	1. Ronna Johnson & HH staff	1. Manual to be completed by January 1, 1996		1. Complete
	2. HH and HLF staff meet to review HH training manual to assess for integrity of the PPCS model.	2. Ronna Johnson, Rita Enlow, Gary Schultz, Jeff Land, Carey Anderson, Denise Isackila	2. January 10, 1996 at 1:30 at HLF	2. Notes from this meeting are in HH/PPCS book.	2. Complete
	3. Respond back to HH with HLF comments from 1/10/96 meeting early in the week of 1/15/96.	3. Carey Anderson, Gary Schultz, Denise Isackila	3. Phoned 1/19/96. Letter sent 2/6/96	3. Notes from phone conversation with Jeff Land and copy of Letter sent Jeff is in the HH/PPCS book.	3. Complete
	4. Completed SFCP Training Manual	4.	4. 5/30/96	4.	4. Complete

Conference - Collaboration for Family Vision '96	**1. Discuss grant requirement to assist replication sites in hosting a conference and therefore the need for them to participate in Family Vision '96. Discuss conference possibilities: breakout sessions & exhibits.** **2. Discussion & brainstorming for Conference breakout session facilitated by HH.** **3. Information for moderator paragraphs to introduce HH breakout sessions** **4. Presentation at Family Vision '96 Conference**	**1. Jeff Land, Rita Enlow, Carey Anderson.** **2. Jeff Land, Rita Enlow, Carey Anderson** **3. Carey Anderson** **4. Rita Enlow**	**1. Meeting 3/5/96. Follow up letter sent 3/8/96** **2. 3/6/96** **3. 5/30/96** **4. 6/4/96**	**1. ** Opportunity was also taken at this meeting to update replication activities, address issues & answer questions.** **2.** **3.** **4. Notes from presentation are in HH/PPCS book**	**1. Complete** **2. Complete** **3. Complete** **4. Complete**
Funding - **Letter of Support** **Grant Application to the Cleveland Foundation for funds to provide Respite for HH Foster Families.**	**1. HLF staff to write a letter of support to support HH efforts to obtain grant moneys to pay for respite.** **HLF staff also assisted in discussions related to the evaluation plan for the grant application.**	**1. Carey Anderson., Gary Schultz, Denise Isackila, Janet Mc Peake**	**1. Letter mailed 3/5/96**	***** Received notification from Rita Enlow on 6/21/96 that HH had received $176,000 for 30 months from the Cleveland Foundation to provide respite for Foster Families.**	**1. Complete**

Specialized Family Care Program - Respite Training	**1. First training presented.** **2. First training to be observed by HLF-PPCS staff.** **3. Second training is set to begin September 24, 1996 .**	**1. Rita Enlow, Ronna Johnson, Jeff Land** **2. Carey Anderson, Gary Schultz** **3. HH- SFCP staff**	**1. 4/18/96 4/25/96 5/2/96 5/9/96 5/18/96 5/23/96 5/30/96** **2. 4/18/96 4/25/96 5/2/96 5/23/96 5/30/96** **3. 9/24/96**	**1.** **2. Comments and Suggestions were given at the end of each training session.** **3. Some revisions have been made since the first training, including: change in timing of sessions and extended hands on/lab time.**	**1. Complete** **2. Complete** **3. Training schedule 9/24/96 10/1/96 10/5/96 10/15/96 10/22/96 10/26/96 10/29/96**
Policies & Procedures	**Policy & procedures at the replication site including: * Recruitment * Interviewing * Training Intake/Referral Assessment Matching Hands-On-Training Supervisory Visits * Evaluation**	**Rita Enlow and HH-SFCP staff.**	**To be completed by 9/1/96.**	**By September 1, 1996 HH-SFCP will give a copy of processes for Recruitment Interviewing Training Evaluation**	**Complete 9/17/96**

PPCS Evaluation Plan Modifications

The evaluation plan has been refined several times to meet the needs of families served. Many of these changes occurred to lessen the paperwork burden on families also there was no significant responses from the families upon the initial surveys. Some changes were then made in an effort to increase data collection. Surveys and PPCS forms were incorporated in the Community Services Evaluation Plan placing the responsibility on staff. This immensely increased data return and also gave PPCS information regarding the impact of PPCS services on individuals over the age of eight. Major revisions were also made in response to site reviewers recommendations to decrease and simplify the evaluation plan. Although the changes assisted in increasing the sample size from previous efforts, the sample size remained small. The following describes the major changes in the PPCS evaluation plan.

1. The comparison group was dropped for ethical reasons. As a service organization PPCS could not identify needs and then not find means of satisfying those needs.

2. The structured developmental scales, the Kent Infant Developmental Scale (KID Scale) and the Minnesota Child Development Inventory (MCDI) were dropped. Scores from preliminary surveys resulted in limited change of the children developmentally over time as well as these surveys were lengthy and put a strain on families. Unfortunately this presented difficulties in determining PPCS impact on child development. Family and staff interviews are the only documentation of impact on child development.

3. The narrative functional assessment was dropped. This was a subjective assessment completed by PPCS staff addressing the areas of: vision, hearing, communication (receptive & expressive), mobility, functional motor skills (reach, grasp, eye-hand, and motor), self-help (eating, dressing, bathing, toileting), health/medical, social development/temperament, cognitive/environmental problem solving, play/recreation/leisure activities. Initially data was sparse, we attempted staff training to increase the quality of data collected. This data continued to be inadequate for analysis and was dropped after the third year site review. The transition readiness form was dropped for similar reasons.

4. The health data was originally designed to be collected by families on a day by day report. This information was not being completed or returned by families yet the information was deemed important and it became part of department procedure for staff to ask families monthly for the number of doctor visits, emergency room and hospital stays, and days of illness. This greatly improved data collection.

5. Measuring family stress and resources was originally designed to utilize the Parent Stress Index (PSI) and the Questionnaire on Resources and Stress (short form) (QRS). PPCS elected not to use the PSI in order to reduce the number of surveys completed by families and the QRS was used after the third year site review. The QRS was also reduced to the three subscales which produced significant results for the sample including: the subscale related to management and dependency, related to terminal illness, and the subscale related to preference for institutional care. In dropping the other subscales two short scales which PPCS gave with the QRS previously, were added to address family stress and resources; The Stress Questionnaire (Kronenberger & Thompson, 1990) and the Family Focus Intervention Scale, Resource Assistance (Mahoney, et. al., 1992).

6. Cost data has been a stumbling block for PPCS since the beginning of the grant. Originally incurred cost was a day by day report by families. This was too cumbersome for families. An attempt was then made to collect monthly information. This too was not completed by families. The issue was then addressed during family interviews. A few things were realized during these family interviews. First, there was a reluctance to discuss money issues and the cost incurred by families. Second, a lack of knowledge of what cost was incurred due to billing directly to funding sources and third, very general and conflicting information was given from family members. Cost data is still scarce and certainly not formally or consistently being collected. Some anecdotal data is reported and some data from PPCS billing records (for PPCS services) is reported.

7. The evaluation plan originally designed for the stress/resources and satisfaction surveys to be completed by families initially, at 6 months, and then at 12 month intervals. This became an ongoing problem for PPCS.

First, families for a variety of reasons did not complete and return the surveys, and second, surveys were not sent when a child was ill, in the hospital, or when the parent had voiced not to send them surveys. Unending attempts were made to encourage families to complete the surveys and families received the surveys on time. Surveys were then sent every 6 months. The outcome of this made analysis nearly impossible when strictly staying to the 6 month and 12 month intervals. The resolution for analysis purposes was to compare survey results from the first time a survey was completed to the second time the survey was completed. The interval between the two surveys was estimated at 6 months to a year, therefore some analysis can be made between the two.

EVALUATION SUMMARY OF THE PPCS PROJECT

Description of the Sample

Detailed demographic data was collected on 113 of the 208 individuals served through PPCS. These 113 individuals encompass 12 counties in the Northeastern Ohio area. 69 of these individuals were between the ages of birth to 2 years of age when they began receiving PPCS services. 24 of these individuals were between the ages of 3 and 5 years of age, and 20 individuals were between the ages of 6 and 8 years of age. For the purpose of data analysis and service delivery individuals are divided into two levels of care. Those who require level of care I utilize ventilators, tracheostomy, suctioning, oxygen therapy, aerosol treatments, NG or G tubes, postural drainage, IV therapies, dressing changes, or daily injection therapy; 51% of these 113 individuals (n = 58) required level of care I. Those who require level of care II utilize apnea monitors, have seizures, and have ongoing medication and therapy needs; 49% of these 113 individuals (n = 55) required level of care II. 40% of these individuals were female and 60% were male. The individuals served through PPCS have a variety of diagnosis, some of the more common ones include BPD, Cerebral Palsy, Developmental Delay, Gastro-Esophageal Reflux, Hydrocephaly, Microcephaly, Prematurity, Retinopathy of Prematurity, and Seizure Disorder. Table __ is an inclusive list of the diagnosis of these 113 individuals. Of these 113 individuals 46 are currently receiving PPCS services, 42 cases were closed because the individuals no longer needed or wanted PPCS services, 26 cases were closed for a variety of reasons mostly because of lack of funding, and 9 individuals died.

PPCS responds to the requests of the families. The following table lists the most common requests families have for PPCS assistance.

Report of families requests of PPCS for assistance.

Assistance requested with ...	% of families requesting assistance
Respite	82%
Information on Residential Placement	11%
Preschool Information	1%
Support	6%
Equipment resource/needs	9%
Service Coordination	26%
General Information	9%
Coordination of Schooling	4%
Information and coordinate therapies	4%
Transportation	3%

These individuals utilize a variety of adaptive, environmental and medical equipment. The following table expresses the percent of individuals that use these types of equipment as well as the percentage of individuals which need equipment and parent report of why they do not have the equipment that they need.

Equipment usage and need at the time of enrollment in the program

	Currently using	Have an equipment need	Why need is not met
Adaptive	33%	18%	* Lack of information about other programs * Need just arose * Waiting for funding
Environmental	6%	7%	* Money * Need just arose * Waiting for funding
Medical	42%	2%	* Waiting for funding

* There was no significant difference between equipment usage and need for children requiring level of care I or level of care II.

The majority of these individuals live in a home with two adults (72%) with 17% of them living with one adult in the home. Seventy-four percent of families had both the individual's mom and dad living in the home. Twenty-four percent of these families had three children in the home, 31% had two children in the home and in 35 % of these families the individual being served was the only child. Twenty-three percent of these 113 families have more than one child with disabilities in the home. The household composition of 10% of these families has changed since the birth/diagnosis of the child receiving PPCS services and 18% have changed place of residence because of child related issues.

The majority of families (n = 86) reported the mother as the primary care giver for the child. The age of the mothers ranged from 17 to 50 years old with the mean age being 32. Seven families reported that the father takes care of the individual during the day and nine families reported that either a school or daycare took care of the individual during the day. Other individuals were taken care of by nurses, personal care providers, and relatives. When the primary care giver was the mother, father, or relative, they were asked if they would be employed if they were not taking care of the individual. Forty-four percent of these caregivers responded yes. The types of support that these families receive from family, friends, churches, or support groups is summarized in the following table.

Types of support from families, friends, churches and support groups.

	Family	Friends	Church	Support Group	Other
Monetary	2%				4%
Emotional	38%	36%	16%	8%	4%
Respite	6%	3%			4%
Monetary & Emotional	2%		3%	3%	3%
Monetary & Respite					
Emotional & Respite	7%	4%	2%		1%
Monetary & Emotional & Respite	2%	37%			
No assistance	24%		53%	61%	56%
No response	19%	20%	26%	28%	28%

School programs are attended by 66% of these 113 individuals. They attend early education programs (n=35), preschool programs (n = 21), and school age programs (17).

These individuals also receive physical, occupational, and speech therapy. The following table expresses the usage of these three services, the percentage of need for these services and the parent perception of why the y do not have the needed services.

Therapy usage and need.

	Have services	Need services or need more services	Why need is not met
Physical Therapy	66%	35%	* No program * Limited program * Lack of information * Need just arose * Waiting for funding
Occupational Therapy	57%	31%	* No program * Limited program * Lack of information * Need just arose * Waiting for funding

Speech Therapy	43%	28%	• No program • Limited program • Lack of information • Conflict of scheduling • Need just arose • Waiting for funding

In order to describe the financial situation of families receiving PPCS services an attempt was made to obtain the income level of families receiving services. The information collected follows:

Income Range	Number of Families
$ 0 - 11,500	2
$ 11,501 - $ 20,500	7
$ 20,501 - $ 27,258	1
Less than $ 27,258	32
$ 27,259 - $ 37,759	8
$ 37,760 - $ 48,260	12
$ 48,261 - $ 62,261	2
$ 62,262 - $ 79,762	1
$79,763 - over	1

* 57 families chose not to report their family income

Of those who reported their family incomes the range of family income for those with children receiving level I care was $12,000 - $64,000 the mean family income was $34,336.30. Of those who reported their family incomes the range of family income for those children receiving level II care was $16,500 - $58,000, the mean family income was $ 32,983.33.

Sixty-two of these 113 families have insurance which covers their child. The majority of these 62 families had insurance which covers 100% or 80% of their child's medical care. Of those families who receive level I care (n=58), 26 of them have insurance which covers their child. Of those families who receive level II care (n=55), 36 of them have insurance which covers their child.

In most cases, families received financial assistance in addition to health insurance to cover the medical needs of their children. The table addresses the usage of some of the additional sources of financial assistance utilized by these individuals.

Number and percentage of families reporting additional assistance with costs.

Funding Source	N	Percentage
Social Supplemental Income	32	28%
Bureau for Children with Medical Handicaps	33	29%
Trust Fund	1	1%
Medically Needy Program	4	4%
Medicaid	43	38%
I.O. Waiver	18	16%
Waiver IV	11	10%
Waiver V	7	6%
Donations	3	3%

Diagnosis represented in PPCS sample (n = 113)

Diagnosis	Frequency
Alexander's Disease	1
Amnionic Band Syndrome	1
Anemia	1
Apnea	2
ARDS	1
Arnold - Chiari Deformity	1
Arthrogryposis	1
Asphyxia	1
Asthma	4
Atypical Lung Disease	1
Autism	1
Biliary Atresia	1
Birth Asphyxiation	1
BPD	26
Bronchotrachealmalacia	1
Central Hypoventilation	1
CHP/CHF	5
Chromosomal Abnormality	1
Chromosomal Translocation	1
Cloacal Exstrophy	1
Congestive Heart Failure	1
Cornelia De Lange	1
CP	12
Cystic Fibrosis	1
Developmental Delay	8
Diabetes	1
Diaphramatic Hernia	1
Down's Syndrome	2
Encephalopathy	2
Endocarditis	1
Epilepsy	1
Erb's Paralysis	1
Failure to thrive	1
Frontal Lobe Anomaly	1
Fundoplication	1
Gastro-Esophageal Reflux	5
Global Delays	2
Glutaric Acidemia	1
Golden Har Syndrome	1
Gtrade IV Ventricular Bleed	1
Heart Block	1
Heart Problems	1
Hemohyperplasia	1
Hip Dysplagia	1
Hydrocephaly	9
Hypoglycemic	1
Hypotonia	1
IGG Infusion	1

Ileostomy	1
Intrauterine Growth Retardation	1
Kidney Reflux	1
Klippel Trenaunay Weber Syndrome	2
Lesion on Brainstem	1
Lennox-Gesteau	1
Leukodystrophy	1
Lissencephalous	1
Microcephaly	6
Miller-Dieken Syndrome	1
Mental Retardation	3
Muscle Disorder	1
Myelomeningocele	1
Nephrocalcinosis	1
Neuromuscular Disease	1
Optic Dysplagia	1
Opukula Syndrome	1
Osteogenesis Imperfecta	2
Pachygyria	2
Para Encephalus	1
Paraplegia	1
Perforated Ulcer	1
Prader Willie	1
Prematurity	23
Profound Hearing Loss	1
PVL	1
Pyloric Stenosis	1
Reactive Airway	2
Reflux	3
Renal Failure	1
Respitory Dysplagia	1
Respitory Failure	1
Retinopathy of Prematurity	6
Seizure Disorder	33
Septal Defect	1
Severe Anoxia	1
Severe Head Trauma	1
Shaken Baby Syndrome	1
Smith Lemli Opitz	1
Spina Bifida	2
Static Encephalopathy	1
Subglottic Stenosis	1
Traumatic Brain Injury	1
Tracheal Malasia	1
Tracheostomy	2
Tuberous Sclerosis	1
Universal Delay	1
Urinary Incontinence	1
Visually Impaired/Blind	1
Werdnig Hoffman Disease	2

IMPACT OF THE PPCS PROJECT

The impact of the PPCS Model has been evaluated utilizing formative and summative methods, including: surveys, questionnaires, service documentation, and interviews with families, project staff, and community service providers. These techniques have allowed for a triangulation of data with quantitative data being strengthened by qualitative data. Evaluation measures were utilized in three ways. One, to collect pertinent information necessary to provide quality services; Two, to evaluate satisfaction and collect suggestions for improvement of service delivery, and three, to document project impacts on families, children, and communities. Results are reported in accordance with the evaluation plan.

IMPACT OF THE PROJECT: FAMILIES, STAFF AND OTHER COMMUNITY AGENCIES AND PROFESSIONALS WILL RECEIVE TRAINING, SUPPORT, AND COORDINATION SERVICES TO ENSURE MAXIMUM INCLUSION OF CHILDREN AND FAMILIES.

Data Sources Interviews: Family, Staff, and Community Providers.
Questionnaires: Family Information Report, Questionnaire on Resources and Stress, Family Focused Intervention Scale - Resource Assistance, Stress Questionnaire, Parent Satisfaction Survey, Respite Satisfaction Survey, Respite Training Program Evaluation Survey.
Documentation: Home Visit Notes and Service Coordinator Notes.

Project Impact on Families:

Training:

Formal and informal inservices and trainings were offered to families on a variety of topics. Some of these included: the Individual Family Service Plan process when a child has a medical need, Individual Family Service Plan Development, funding sources for families with medical needs, community resources, permanency planning, and issues of death and dying. PPCS staff provide informal training as part of their service coordination activities and monitoring of respite care services through interaction with families including: knowledge of the laws, Ohio policy, and family/child rights, as well as medical, educational, therapeutic and general care information specific to children with chronic health care needs. One mom during a family interview stated that her child had recurring infections but that her PPCS nurse taught her about disinfecting and the recurring infections had decreased. PPCS staff, during staff interviews, stated that a strength of the model was the emphasis on " ... trying to teach families how to do things on their own...families could always utilize us in the future, but they would also know how to find resources."

Community providers commented during phone interviews that families involved with PPCS demonstrate knowledge and abilities in the Individuals Family Service Plan and Individual Education Plan processes. PPCS training and consultation with community providers has had a positive indirect effect on training for families. Other professionals and agencies expressed an increase in their ability to provide families with information ranging from equipment to diagnosis because of their involvement with PPCS staff.

A large portion of PPCS efforts are directed towards the training of Specialized Respite Care Providers. This extensive process impacts families. One family commented that "the Hands-On-Training was terrific! in terms of the amount of attention and detail paid to the family and training versus other agencies who only send paper, not people". The Respite Satisfaction Survey was designed to asses the family's satisfaction with the quality of respite services they were receiving from PPCS. The Respite Satisfaction Survey addresses parent perception of: how safe the family feels with their child in the providers care, satisfaction with the knowledge and training of their provider, the providers compliance with requests, and how the provider reacted in an emergency situation. This survey is given to families every 6 months and the results from the first three surveys are reported in Table 1. This survey along with

family interviews provides families a way to tell us what they like and don't like about the providers, respite services, and the impact respite services has had on their family. Some of the comments of families follow.

- "We feel safe and secure leaving our child with providers trained through PPCS.
- "...providers trained through PPCS were the best that have ever taken care of our children."
- "Providers know what to look for."
- "This summer has been the most fulfilling we've had since our child's birth. The family can plan and schedule activities and the providers are flexible."
- "My provider is well organized, knowledgeable and takes the initiative in caring for my child even when I am at home."
- "Nurses are very friendly yet professional. Very knowledgeable. They have lots of patience with a special baby like ours. They are very helpful with answering questions we have."
- "Because the program providers are better trained than other providers. I feel they are better at picking up on my child's needs."

While families stated their appreciation of high training standards, they also mentioned one negative impact of specialized recruitment, training, and maintenance of a network of highly specialized respite care providers...it takes time/the wait to get a provider.

Support:

Families receive support from PPCS Service Coordinators, Community Health Professionals, and Specialized Respite Care Providers.

Families receiving PPCS services have said that receiving these services has had an impact on their family stress. This has been measured through the use of the Questionnaire on Resources and Stress (Holyrod, 1981), an adapted version of the Family Focused Intervention Scale, Resource Assistance (Mahoney, O'Sullivan, and Robinson, 1992), an adaptation of the Stress Questionnaire (Kronenberger and Thompson, 1990) and is further defined through comments collected during family interviews.

All adaptations were made with author approval. Results were explained to service coordinators who in turn shared the information with families. Consistently, staff indicated prior knowledge of stressors within a family, as indicated on the stress measures, based on previous discussions and involvement with the families.

Measures of Family Resources and Stress were administered initially, at 6 months, and then yearly to families receiving PPCS services.

Questionnaire on Resources and Stress (QRS) (Holyrod, 1981)
The subscales assessing Management and Dependency, Terminal Illness Stress, and Preference for Institutional Care were utilized. The results of this survey are summarized in Table 2 and Table 3. Scores were compared per item between the first time families completed the survey to the second time the families completed the survey. The interval of time between surveying was approximately six to twelve months. (Third time surveys have been collect but are not reported here due to sample size). Also reported in Table 2 and Table 3 are responses to items as stratified by the level of care required by the child and the age of the child when they began receiving PPCS services.

A Mann-Whitney U determined there was no significant difference between responses at time one and time 2. A Mann-Whitney U was completed to determine differences between those requiring level I care compared to Level II care within each test administration. This expressed two significant results. Within the time 1 test there was a significant difference ($p = .0511$) between responses on item 13 and within the time 2 test there was a significant difference ($p = .0451$) between the responses on item 9 appearing to

indicate that those families with children requiring level I care were more worried that their child could sense that they did not have long to live than those children requiring level II care.

Table 3 expresses responses to the QRS as stratified by the age of the child when they began receiving services. Mann-Whitney U was completed to determine significant differences within test administrations when distributed by age. The following expresses significant results. Within the time 1 test administration significant differences were found between those with children birth to two years and those with children three to five years on item 15 ($p = .0115$); suggesting that families with older children were less optimistic that they could keep their child at home. Although at the second test interval, most all families agreed that it was possible to keep their child at home. Also, during the test 1 interval, significant differences were determined between families with children birth to 2 years and those six to eight years on the following items: Item 4 ($p = .0167$), Item 8 ($p = .0269$), Item 11 ($p = .0023$) and Item 12 ($p = .0063$). Items eight, 11 and 12 all refer to the Terminal Illness Stress subscale and appear to indicate that those with older children responded in a more stressful manner than those with children birth to two years. Within the second test administration there was also a significant difference between those families with children birth to two years and those with children six to eight years on item 11 ($p = .0123$). Other significant results within the second test administration were on the dependency and management scale; item 2 ($p = .0135$) between families with children birth to 2 years and those with children three to five, item 4 ($p = .0381$) between families with children three to five years and those with children six to eight, and item 4 ($p = .0280$) between families with children birth to two years and those with children six to eight years.

The Stress Questionnaire (Kronenberger & Thompson, 1990) and an adapted version of the Family Focused Intervention Scale, Resources Assistance (Mahoney et al., 1992) were administered to determine other areas of stress and resources not covered by the QRS. The Stress Questionnaire is divided into two factors; the Child/Medical Stress Factor and the Social/Non-child Stress Factor. Each item is rated on a seven point Likert scale 1 (not at all stressful) to 7 (extremely stressful). Table 4 and Table 5 report the results from the Stress Questionnaire from time one to time two, stratified by level of care and child age. There were no significant differences between families responses from time one to time two. There were also no significant responses within test one or within test two when stratified by the level of care required by the child. There were some significant results when stratified by the age of the child, although they seem to be due to the age appropriateness of the question on one item and due to sample size in other cases and therefore, are not reported here.

The Family Focused Intervention Scale, Resource Assistance (Mahoney, O'Sullivan, and Robinson, 1992) was administered because of it's additional look at time and money issues. The items were rated on a five point Likert Scale 1 (not at all adequate) to 5 (almost always adequate). Table 6 and Table 7 report results from the Family Focused Intervention Scale, Resource Assistance from time one to time two, stratified by level of care and child age. The interval of time from test one to test two was six to twelve months. A Mann-Whitney U demonstrated a significant difference between scores from time one to time two on two items; item 7 ($p = .0349$) and item 14 ($p = .0358$). This finding is significant, appears to indicate that after beginning to receive PPCS services families found time for family to be together and money to buy special equipment or supplies for their children to be more adequate. When a Mann-Whitney U was completed to assess difference within test one stratified by level of care, there was a significant difference on item 3 ($p = 0511$). This appears to indicate that those families with children requiring level II care have more adequate medical care for their family than those with children requiring a higher level of care. Some significant results were found within test two when stratified by child age but caution was taken in terms of interpretation due to small sample size and therefore the results are not reported here.

Although significant results from the three measure used to address family stress and resources were few, these measures were definitely useful functionally to PPCS. They confirmed staff perceived stressors, were used as a tool to facilitate discussion, and when given initially at the beginning of receiving services. It assisted service coordinators in prioritizing their assistance efforts. It is also felt that with increased

sample size and more than one interval of measurement, significant results would be found. The following are comments from family interviews regarding the impact of PPCS services on family stress:

* " It alleviated the stress of whether or not I would have to quit my job - that was a big issue."
* " It eased stress of the system of the waiver, how to do it."
* " PPCS gave me someone to talk to, someone to understand."
* " Decreased frustration because I know where to get answers."
* " The program took away stress, especially for me."
* " Respite helps lessen stress because I have time to do what I want or need to do."
* " Definitely relieves stress. Especially when my child has difficult days."

The Parent Satisfaction Survey (PSS) (Project Dakota, 1989) was adapted with permission from it's developers of Project Dakota to examine family satisfaction with PPCS. The adapted PSS is comprised to evaluate family's satisfaction with three areas. 1) Program and Staff Responsiveness, 2) Utilization of Community Services, 3) Building a Support System. Each item on the PSS is rated twice utilizing two 4 point Likert Scale. Each item is first rated to assess how much the family agrees with each item 1 (strongly disagree) to 4 (strongly agree). Then each item is rated again for how important the item is to the family 1 (not important) to 4 (very important). Table 8 reports results from the agreement portion of the PSS from time one to time two for each item. The interval of time from test one to test two was six to twelve months. The portion rating the importance of each item, although useful functionally, unfortunately was often not completed by families and therefore results are not reported here.

Reflected in Table 8 are the responses of families over time. It is apparent that the majority of responses indicate family satisfaction. To further strengthen these results the following are comments of family satisfaction with the PPCS program collected from family interviews.

* " With many agencies the providers consider this just a job. With PPCS, I have always felt that you make sure providers do care for the children. Not just physical needs met but actually emotionally care for the children."
* " I appreciate all the answers PPCS has. Almost everyone I talk to at PPCS knows more about the waiver than people at the waiver program."
* The program has helped our family a great deal. We spend better quality time with the whole family."
* " Three years before I was on this program I was always on my own fighting battles."
* " I'm relieved that now I know where to go, before I felt I was out there by myself."
* " PPCS, is more concerned with the whole family."

Coordination Services:

Families receive coordination services mainly from PPCS Service Coordinators. A family's initial request for assistance with coordinating services is documented on the Family Information Report. Individual reports were reviewed for 113 children to summarize the types of assistance families requested. The

majority of families first request is for assistance with coordinating respite services (82%). Many families request general service coordination not usually specific to a particular service (26%). A little over 10% requested specific assistance with financial / waiver information (11%). A little under ten percent of families requested assistance in meeting equipment needs and finding resources (9%). General information was also requested by 9% of families. Other requests for coordination of services include: support (6%), coordinating schooling (4%), information and assistance coordinating therapies (4%) and assistance with transportation (3%).

In order to document progress toward requested services as well as document new requests as they arise service coordinator home visit notes are completed. These notes are kept in such a way to facilitate and empower of families. These notes document the current priorities and concerns, issues to be followed up by the service coordinator, and issues to be followed up by the parent or guardian. This form is completed at the end of each home visit. For the purpose of evaluation 261 home visit forms which encompass 37 families are summarized here. The most common family priority/concern discussed during home visits was funding (16%). Other priorities / concerns discussed during home visits include: Equipment (21%), Respite (10%), Child health issues (8%), Schooling (7%), Therapies (5%), Behavior issues (2%), Family issues (2%), Individual education or service plans (2%), recreation (2%). The following are the areas documented for service coordinator follow-up at the end of the visit: Equipment (37%), Funding (28%), Respite (18%), Individual education or service plans (13%), Therapies (10%), Schooling (5%), Transportation (3%), Medical (2%), Recreation (2%), Appointments (1%). In a constant effort to teach and empower families at the end of each home visit issues to be followed up by the family/parent are documented. The following summarizes the areas to be followed-up by parents: Funding (3%), Equipment (13%), Therapies (8%), Appointments (6%), Individual education or service plans (5%), Schooling (4%), Respite (4%), Transportation (2%), Medical (1%). Along with this documentation of assistance in coordinating services families were asked during family interviews about the assistance they received from PPCS, the following are some of their comments:

- "Our service coordinator did most of the work getting us respite, she requested information from other professionals. She got PT and OT services started and she came to my child's doctor visits with me."

- "The Service Coordinator got us on Waiver IV and helped us with SSI. She went with us to meetings and got us involved in a support group."

- "The Service Coordinator intervened with the school psychologist which got us into MR/DD program and my child will next fall be in public school."

- " The Service Coordinator told me what was available in the area and what my child's rights are. She coordinated a whole lot of things. I wouldn't have known where to go."

- "Our Service Coordinator came to my child's Individual Education Plan meeting. She coordinated delivery of equipment, she amended my child's plan for homemaker-personal care hours, and was always helpful in getting current information to me."

Staff

Training, support, and coordination services is provided to our staff as well as the families we serve and other community professionals.

Training:

Staff training is accomplished on an on-going basis as needs and opportunities arise to maintain quality. Staff attended over 75 inservices related to families and children with complex medical needs. "Both

inside and outside of the office, we are constantly training others and training each other..." according to one of the PPCS service coordinators. Fundamental to the model is the utilization of a transdisciplinary teach approach in service delivery and staff development. Information obtained through inservices, state and local committee activities, journals and books is shared as a part of weekly team meetings.

Support:

Staff expressed feeling supported through weekly team meetings and individual consultations between service coordinators. "I think it is an extremely supportive project, supportive of each other and supportive of our families" stated one of the service coordinators. Project staff also receive administrative support in their professional and personal development as evidenced by encouragement, financial assistance, and comp time to attend training. Evidence of adherence to the principles of family-centered care, staff expressed feelings of administrative support "... to be flexible in scheduling visits with families and around family priorities...a level of support that has enabled (me) to meet a family on a Saturday afternoon instead of a Tuesday..."

Coordination services:

One of the strategies utilized by project staff in coordinating services is developing and maintaining extensive informal and formal networks at a national, state, and local level. These networks provide a stream of state-of-the-art information on families, children, funding and resources, and systems change. A PPCS staff member remarked, "Others look to us to have information because we make it a point to find what the most recent things are." Other staff commented that the team process of information sharing and problem-solving assisted the project staff to remain current on available resources and services, and confident they are offering families all options available.

When staff were asked in what ways they felt the project has been instrumental in ensuring children with complex medical needs and their families are maximally included, responses included: advocacy efforts on county collaborative groups; making families more aware of community opportunities (e.g., accessible recreation activities); and, promoting concepts of normalization, least restrictive environments, family focus, and person first language and attitudes. "Hopefully, it is helping get our kids (and families) we are working with assimilated into the community...into normal situations."

Project impact on community service providers

PPCS has trained over 200 respite providers since October of 1991. This training is an extensive 40 hour experience, including the Specialized Respite Training Course, CPR and First Aide training, two hours of Hands-On-Training in the families home with the RN assessor present, and four hours supervised time in the family's home with the family present. Along with this training providers are expected to complete 12 hours of ongoing inservice training hours a year. This training can be accomplished through inservice articles published in 'The Key' a newsletter put out by the department. Table 9 illustrates responses to the brief Respite Training Program Evaluation completed at the end of the Respite Training Course (n = 177). When participants were asked to rate the program 56% responded it was excellent and 42% responded it was good. Of the remaining two percent, 1% responded it was fair and 1% responded it was poor.

After completing all training and providing respite for at least two weeks, providers are sent a more detailed evaluation of the entire training process; Table 10 reflects response on the Respite Provider Training Survey. This survey was not developed or implemented until late in the fourth year of the grant which explains the small sample size (n = 15), but it has proven very worthwhile and will continue to yield important evaluation information in the future. This survey is comprised of two types of questions; rating items on a seven point Likert Scale (Table10) and open-ended questions addressing increase in knowledge, skills, and general comments about the program and materials used for training; some of which are summarized below:

Areas where your knowledge has increased:

* "The course was full of facts and was helpful as far as information."
* "I found the respite training a great refresher and very informative. The newsletter articles are also helpful."
* "All of my knowledge came from the course. I had never worked with children with medical needs."
* "Discussions on seizures and g-tubes helped prepare me for my current client."

Areas where your skills have increased:

* "The in-home training is great because I learn specific ways that work with and for the specific child. How to hold/support him to walk, how he takes his pills, etc.."
* Prior to PPCS I had never worked with nonverbal individuals and my training prepared me for the special challenges involved.
* "Giving medications and feeding via G-tube. Proper lifting and transfer techniques.

General comments about the program and training materials used.

* "They are so thorough about the care that should be given to the individual."
* " I have needed very little assistance from PPCS since my training, but during training I was very impressed with the amount and relevance of the information."
* "All those I have worked with have been committed and professional."
* " I really appreciate being able to use the training articles from 'The Key' for my training hours. They have good useful information."
* "Written materials/respite book is very informative."

Along with training specialized respite care providers, PPCS has provided training to a variety of community agencies and professionals on a variety of topics. During phone interviews with professionals within the community, providers were asked "In what ways has our program assisted you in ensuring that families and their children with chronic medical needs are maximally included in their community?" Training and technical assistance was perceived as the training of service providers within the community. The majority of community providers talked to, felt the PPCS training and technical assistance had broadened their knowledge and impacted positively on their attitude towards children with chronic medical needs and their families. Sixty - seven percent felt PPCS staff had been helpful in expanding their skills with this population and their families.

During telephone interviews community members expressed increased awareness of family priorities, resources (and lack of), concerns and the needs of children with chronic health conditions through PPCS staff involvement on local planning groups and state subcommittees. " They brought the needs into the community ... public ... provided more information to the general public about what are the needs and what to do." Several stated that interagency collaboration and team planning was of great assistance in coordinating services with families. "Very cooperative ... helpful at team meetings ... very positive experience."

Beyond the impact on community provider's, families were asked there perception of PPCS impact on their community. The following are families comments.

* "The service coordinator always said if I get my child out in the community and let them ask questions then the community will be more apt to let him in schools. Get him involved in extracurricular activities; safety town, and high school daycare."

* "The service coordinator encouraged me to take him out. We got a few baby-sitters from the community. Now he is the mascot for the community softball team."

* "Increase in awareness of the community, as well as our own awareness."

- "In a round about way, contact with PPCS has made me more bold to speak out. Also I take my child out in the community regularly. It has made me more determined to go out into the community."
- "I do feel the community awareness may be increased by the fact that I tell people in the community what a help it is to have respite and how wonderful the nurse is."
- "I can go to school and spend more time with my other kids. Like my son's football games, they know I have a handicapped kid."
- "I get notices from PPCS about what is going on in the community and it gets me out there more."
- "It really helps to have the nurse go with me when I want to take my child somewhere. We recently went to a festival and the nurse went too."

IMPACT OF THE PROJECT: CHILDREN WITH CHRONIC HEALTH CARE NEEDS WILL RECEIVE APPROPRIATE SERVICES IN THEIR HOMES AND COMMUNITY ENVIRONMENTS AS SELECTED BY THEIR FAMILIES.

Data Sources Interviews: Family and Staff.
Questionnaires: Family Information Report, Kent Infant Development Scale, Minnesota Child Development Inventory.
Documentation: Service Coordinator Notes, Monthly Child Health Documentation .

Impact on child's development:

Initially project impact on child development was measured using the Kent Infant Development Scale (KID) and the Minnesota Child Development Inventory (MCDI). Preliminary results from the first three years of the project demonstrated varying differences in utilizing these scales there was no way to tell if the differences were due to PPCS services. In light of these findings along with the knowledge of the burden completion of these surveys put on families, the decision was made to abandon the use of these surveys. The following are summaries of preliminary findings to demonstrate the types of variance found utilizing these scales. Names in the following summaries have been changed to protect anonymity.

Summaries of children requiring licensed level of care (Level of Care I):

Larry was less than two years of age and his developmental level was evaluated with a KID scale initially when he began using services and again one year later. His full scale score increased from 3.8 months initially to 11.3 months when he was evaluated a year later. He showed developmental increases in all subscales of the KID scale generally progressing nine months in each scale with the exception of motor development were he progressed five months.

Laurie also was younger than two years of age. She was given the KID scale at the initial point of involvement with PPCS and again six months later. In six months time her full scale score increased from 2.5 months to 7.9 months. Her strongest gains over this six months interval were in the scales addressing social development, an eight month gain. For Laurie the least amount of gain was in the area of motor development, a 3.9 month gain.

Kevin was less than two years of age when evaluated by a MCDI given six months after enrollment with PPCS and at 12 months. In this 6 month interval Kevin's developmental scale score increased from 23.0 months to 31.5 months. His greatest developmental gains were in the situation comprehension scales, a 10.5 month gain, and the expressive language scale, an 8.5 month gain. Smallest gains developmentally for Kevin were made in the self help scale, .5 month gain, and the personal social scale, a 1.5 month gain. Range of developmental advances in this 6 month interval were from .5 months to 10.5 months.

Rebecca was between the ages of three and five years. She was given the MCDI at three study points; initial, 6 months, and 12 months. Rebecca's developmental scale at initial point was 37.5, six months later she had gained six months in development, at the 12 month point she had gained another 13.5 months, therefore the 12 month point Rebecca's developmental scale was 57.0 months. With her greatest gains over the full year in the conceptual comprehension scale, a 25.5 month gain, the fine motor scale, a 15.0 month gain, and the personal social scale, a 9 month gain. Her situation comprehension scale and expressive language scale scores stayed the same over the year at 42.0 months and 36.0 months respectively.

Cathy was between the ages of six and eight years old. She was evaluated with a KID scale initially and 12 months later. Her full scale score increased from .7 months to 1.4 months in 12 months

time. Her largest gains in this month time was in the language scale and the self help scale both with a 1.5 month increase. Other scale gains were small, ranging from .3 to .6 months.

Summaries of children requiring unlicensed level of care (Level of Care II):

Allen was less than two years of age and was given the MCDI at initially and again six months later to evaluate his developmental level. In six months time his developmental scale decreased from 28.5 months to 16.0 months. Allen stayed developmentally the same on the gross motor scale, at 7.5 months, and decreased on the conceptual comprehension scale, a 19 month decrease. Other decreases ranged from a 4.5 month decrease to a 13.0 month decrease.

Nick also was younger than two years of age. He was given the KID scale initially and one year later. Initially his developmental level was at 3.6 months, a year later it had just about stayed the same but decreased a little scoring at 3.4 months. Nick's scores decreased on three of the scales with his greatest decrease on the motor scale, .8 months decreased. He decreased .3 months on the self help scale and the social scale and had small increases on the language scale, .5 months and the cognitive scale, .2 months.

Colleen was between the ages of six and eight. She was evaluated with the KID scale initially and one year later. In these 12 months her full scale score from 4.8 months initially to 6.8 months. Colleen's greatest gains were on the social scale, a two increase from initial 5.4 months to a year later 7.4 months. Other gains ranged from 1.4 months to 1.8 months with her strongest scores on the language scale scoring after one year at 7.7 months.

After abandoning the MCDI and KID scales, the family interview became the means of collecting the impact of the project on child development. The following are family comments regarding PPCS impact on their child's development:

- "I always had a lot of questions about my child's development. The service coordinator got answers about his development. She got a multifactor evaluation done so they could get answers. She also helped me get testing on his cognitive development"
- "Providers are very good with his exercise and I can see improvement."
- "Provider works with helping my child walk."
- "A little because the providers do therapy, not tremendous breakthrough though."
- "Her developmental growth is a constant. Every time a provider is here, a certain amount of time is devoted to some type of developmental growth, i.e. sitting up, reaching for objects."
- "The nurses work with the therapists who come to the home. Since they're usually here, they are able to continue programming."
- "The provider has a real positive effect on my child. My child probably wouldn't be this far without the provider's involvement. The providers have learned to put their foot down and be strong with my child, which really helps him. My child is very stubborn."
- "Some providers take him out for walks. These are good things and help him with social development."
- "My child learns social skills, by being around other people"
- "More time for one on one stimulation, exercise, and massage."

Impact on child's health:

Information of PPCS impact on the individuals health was collected through staff documentation and family interviews. Each month PPCS staff document the number of doctor visits, clinic visits, emergency room visits and hospitalization from parent report. Table 11 and Table 12 demonstrate the means of visits per month over time. Table 11 further details the year mean for doctor visits, emergency room visits, and hospitalizations stratified by the age of the child. These tables set the ground work for describing health trends of children with chronic health care needs, but at this time any conclusions would be quite subjective. In an attempt to further look at the impact of PPCS on individual health, family interviews were once again utilized. The following are family comments regarding the impact of PPCS on their child's health:

- "Having a provider allows me to leave my child home on days when being out could potentially make her sick."
- "My child does not have to go out all the time. If I can't call off of work, I don't have to take him outside or to a daycare where there may be germs that he can't tolerate."
- "He eats much better now if someone else is feeding him."
- "Not having to go out and keeping him home is keeping him healthier."
- "Emotionally, my children have better emotional health, because I was more relieved - they were healthier."
- "Nurses answer my questions and identify problems early."

For descriptive purposes the following information is reported regarding those individuals who received PPCS services who have died. Fifteen children in total died, eleven of them were female and four were male. Eleven of these children were between the ages of birth and two years, three were between the ages of three to five years, and one child was between the age of six and eight years. The majority of these children required level I care (n = 10), while the remaining five required level II care. Five of these children had seizure disorder, three children had cerebral palsy, and three children had microcephaly. Other diagnosis present in this group were; Miller-Dickers Syndrome, Golden Har Syndrome, Congestive Heart Failure, Trisomy 18, Hydrocephalus, and Werdnig-Hoffman Disease. Ten of these families received PPCS service coordination and five of these families received PPCS respite services.

Impact on cost to families:

PPCS set out to do two things in terms of cost issues. One, describe a picture of what it costs families to take care of children with chronic health care needs; and two, to compare costs of home-based care and institutional care. These cost issues were by far PPCS's biggest stumbling block. PPCS began by talking with families regarding the costs of taking care of children with chronic health care needs, one thing became apparent - many families didn't know. Families reported that they didn't see many of the figures due to them being handled by insurance or a variety of funding sources. Beyond this, many families expressed concern in discussing money matters. There was an ever present fear that by discussing the issue they may loose funding that they already had. The discussion with families regarding cost then slightly changed focus. Families were asked what impact did PPCS have on your financial situation. Families comments follow:

- "PPCS services helped me keep my job. I didn't have to quit work."
- "Service coordinator helped us get assistance from Easter Seals and equipment from there. She helped us apply for the Waiver and for BCMH."

- "Problems with SSI. The service coordinator helped with the appeal process. She helped to find financial assistance after loosing a program like the waiver."
- "Able to work and have an income."
- "Medically trained help. I don't pay anything at all for it and it is a great help. I can go to school."
- "Allows me to work (career) as well as the respite allows her to go out on the weekends to relieve stress."
- "We could not afford this type of nursing respite without the set-up that PPCS has. (County Contract)."
- "No waiver, no respite, I wouldn't be able to work."

Although there was a documented impact of PPCS services for these families, PPCS still could not pin down cost for the care of children with chronic health care needs. Analysis of the cost of PPCS services these families could not give us a picture of the needs of these families because often times the amount of services they receive is directly related to their funding source and not necessarily the needs of the family.

Not being able to quantitatively answer the first cost question made it virtually impossible to answer the second regarding the comparison of the cost to take care of these children in the home versus in an institution. In home variables could not be isolated without significant intrusion for the families served. Although this area is a difficult one in which to find answers, the impending world of managed care is insisting that answers are found. The Hattie Larlham Foundation has directed it's efforts towards defining chronic health care costs both institutionally and in community care. PPCS staff have been active in this effort sharing information learned during this project. It is the Hattie Larlham Foundation's intention to work collaboratively with the state of Ohio to continue to address the cost issues that effect this population, especially in regards to how they will be served by a managed care model.

Table 1. Respite Satisfaction Survey
Family responses over time.

Item	May 1995 n = 20	Nov. 1995 n = 29	May 1996 n = 30
The respite provider in your home is a			
RN	3	1	0
LPN	11	9	13
Personal Care Provider	8	19	17
Provider's Appearance			
Good	100%	100%	96.7%
Fair			3.3%
Poor			
Provider's Attitude			
Good	100%	100%	100%
Fair			
Poor			
Provider's Techniques			
Good	95%	93.1%	96.4%
Fair	5%	6.9%	3.6%
Poor			
Provider's Punctuality			
Always on time	80%	82.8%	90%
Often on time	20%	17.2%	6.7%
Seldom on time			3.3%
Never on time			
How safe do you feel your child is while in the provider (s) care?			
5 Very Safe	85%	75.9%	80%
4	5%	17.2%	10%
3 Safe	10%	6.9%	6.7%
2			3.3%
1 Not Safe			
How does your provider (s) blend in with your family environment?			
5 Over controlling in the environment	5%		6.7%
4	5%	10.3%	13.3%
3 Fits Well	85%	86.2%	76.7%
2	5%	3.4%	3.3%
1 Uncomfortable in the environment			
How willingly does your provider (s) comply with your family's routine, requests, and suggestions?			
5 Very willingly complies	75%	69%	73.3%
4	10%	20.7%	13.3%
3 Complies	15%	10.3%	10.0%
2			3.3%
1 Does not comply			
How knowledgeable and well trained is your provider?			
5 More than adequate	55%	55.2%	56.7%
4	30%	27.6%	20%
3 Adequate	15%	17.2%	20%
2			1.3%
1 Not adequate			

How soon did you feel confident to leave your child after training your provider (s)?	26.3%	40.7%	32.1%
After the 4 hours of hands on training	21.1%	25.9%	7.1%
Less than 1 week	26.3%	14.8%	28.6%
After 1 week	26.3%	14.8%	17.9%
After 2 weeks			7.1%
After 3 weeks		3.7%	3.6%
After 1 month			3.6%
Not yet comfortable			
If an emergency has occurred how well did your provider respond?			
Over reacted			3.6%
Had some concerns-some what over reacted		3.4%	
Adequate		48.3%	42.9%
Had some concerns-some what under reacted			
Did not respond			
No emergency		48.3%	53.6%

Table 2. Questionnaire on Resources and Stress (Jean Holroyd, 1987). Subscales 1,7, and 10.
1 - Strongly Agree, 2 - Agree, 3 - Tend to Agree, 4 - Tend to Disagree, 5 - Disagree, 6 - Strongly Disagree

Item	Stress Response	Time 1 Overall n = 43 loc 1 n = 20 loc 2 n = 23 x SD	Time 2 Overall n = 23 loc 1 n = 10 loc 2 n = 13 x SD
1. _____ demands that others do things for him/her more than is necessary.	1 , 2	4.05 1.72 3.75 1.80 4.30 1.64	4.30 1.72 4.30 2.00 4.31 1.55
2. If _____ were more pleasant to be with it would be easier to care for him/her.	1 , 2	5.37 1.22 5.36 1.22 5.38 1.24	5.30 .97 5.40 .97 5.23 1.01
3. _____ is easy to live with.	5 , 6	2.39 1.47 2.32 1.50 2.46 1.47	2.00 1.00 2.10 1.20 1.92 .86
4. _____ doesn't do as much as he/she should be able to do.	1 , 2	3.56 1.85 3.05 1.80 4.00 1.82	3.91 1.88 3.70 2.11 4.08 1.75
5. It is easy to keep _____ entertained.	5 , 6	2.80 1.44 2.81 1.25 2.79 1.61	3.17 1.53 3.00 1.83 3.31 1.32
6. _____ is very irritable.	1 , 2	4.69 1.41 4.43 1.54 4.92 1.28	4.57 1.47 4.70 2.00 4.46 .97
7. I don't worry too much about _____'s health.	5 , 6	5.24 1.12 5.09 1.27 5.38 .97	5.26 .75 5.50 .71 5.08 .76
8. As the time passes I think it will take more and more to care for _____.	1 , 2	3.42 1.70 3.23 1.63 3.61 1.78	3.04 1.46 3.10 1.52 3.00 1.47
9. I worry that _____ may sense that he/she does not have long to live.	1 , 2	5.45 1.25 5.15 1.57 5.71 .86	5.36 1.09 4.90 1.37 5.75 .62
10. I worry about how our family will adjust after _____ is no longer with us.	1 , 2	3.77 2.18 3.55 2.24 4.00 2.14	3.73 2.03 3.10 2.38 4.25 1.60
11. In the future _____ will be more able to help himself/herself.	5 , 6	3.20 1.82 3.32 2.00 3.08 1.67	3.57 1.75 3.40 2.01 3.69 1.60
12. _____ cannot get any better.	1 , 2	4.33 1.83 4.73 1.67 3.96 1.94	4.50 1.41 4.60 1.17 4.42 1.62
13. The doctor sees _____ at least once a month.	1 , 2	2.78 1.63 2.09 1.23 3.42 1.71	2.83 1.64 2.10 1.29 3.38 1.71
14. I would not want the family to go on vacation and leave _____ at home.	5 , 6	2.20 1.65 2.27 1.64 2.13 1.70	1.87 1.36 2.10 1.45 1.69 1.32
15. There is no way we can possibly keep _____ in our house.	1 , 2	5.76 .85 5.73 .63	5.96 .21 6.00 .00

		5.79	1.02	5.92	.28
16. We take _____ along when we go out.	5 , 6	2.27	1.39	2.00	.95
		2.68	1.64	2.00	1.05
		1.87	.97	2.00	.91
17. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.	5 , 6	2.02	1.71	2.29	1.87
		2.27	1.88	2.00	1.80
		1.79	1.53	2.50	1.98
18. _____ is better off in our home than somewhere else.	5 , 6	1.50	1.21	1.26	.69
		1.41	.85	1.20	.63
		1.58	1.47	1.31	.75

Table 3. Questionnaire on Resources and Stress (Jean Holroyd, 1987). Subscales 1,7, and 10.
1 - Strongly Agree, 2 - Agree, 3 - Tend to Agree, 4 - Tend to Disagree, 5 - Disagree, 6 - Strongly Disagree

Item	Stress Response	Time 1 Overall n = 46 Birth - 2 n = 22 3 - 5 n = 11 6 - 8 n = 13 x SD	Time 2 Overall n = 23 Birth - 2 n = 13 3 - 5 n = 3 6 - 8 n = 7 x SD
1. _____ demands that others do things for him/her more than is necessary.	1 , 2	4.05 1.72 4.10 1.61 3.20 1.99 4.67 1.50	4.30 1.72 4.31 1.49 2.67 1.53 5.00 1.91
2. If _____ were more pleasant to be with it would be easier to care for him/her.	1 , 2	5.37 1.22 5.00 1.54 5.55 .93 5.85 .38	5.30 .97 5.61 .65 4.00 1.00 5.29 1.11
3. _____ is easy to live with.	5 , 6	2.39 1.47 2.32 1.32 2.00 1.61 2.85 1.57	2.00 1.00 1.77 .73 2.67 .58 2.14 1.46
4. _____ doesn't do as much as he/she should be able to do.	1 , 2	3.56 1.85 3.00 1.69 3.64 2.25 4.50 1.45	3.91 1.88 3.54 1.81 2.67 2.08 5.14 1.46
5. It is easy to keep _____ entertained.	5 , 6	2.80 1.44 2.76 1.30 2.55 1.57 3.08 1.61	3.17 1.53 2.92 1.50 4.33 1.53 3.14 1.57
6. _____ is very irritable.	1 , 2	4.69 1.41 4.52 1.50 4.91 1.51 4.77 1.24	4.57 1.47 4.54 1.39 4.33 1.15 4.71 1.89
7. I don't worry too much about _____'s health.	5 , 6	5.24 1.12 5.05 1.33 5.45 .82 5.38 .96	5.26 .75 5.38 .65 5.33 1.15 5.00 .82
8. As the time passes I think it will take more and more to care for _____.	1 , 2	3.42 1.70 4.05 1.43 3.09 1.81 2.69 1.75	3.04 1.46 3.54 1.39 3.00 2.00 2.14 1.07
9. I worry that _____ may sense that he/she does not have long to live.	1 , 2	5.45 1.25 5.38 1.20 5.60 1.26 5.46 1.39	5.36 1.09 5.75 .45 4.67 2.31 5.00 1.15
10. I worry about how our family will adjust after _____ is no longer with us.	1 , 2	3.77 2.18 4.19 2.14 3.27 2.37 3.50 2.11	3.73 2.03 3.58 2.15 3.33 2.52 4.14 1.86
11. In the future _____ will be more able to help himself/herself.	5 , 6	3.20 1.82 2.41 1.59 3.45 1.92 4.31 1.55	3.57 1.75 2.85 1.68 3.33 1.53 5.00 1.15

12. _____ cannot get any better.	1 , 2	4.33	1.83	4.50	1.41
		5.00	1.60	4.67	1.30
		4.00	1.95	5.33	1.15
		3.42	1.78	3.86	1.57
13. The doctor sees _____ at least once a month.	1 , 2	2.78	1.63	2.83	1.64
		2.59	1.62	2.31	1.18
		2.91	1.58	3.33	2.08
		3.00	1.78	3.57	2.07
14. I would not want the family to go on vacation and leave _____ at home.	5 , 6	2.20	1.65	1.87	1.36
		1.86	1.39	1.62	.96
		2.64	2.16	2.33	2.31
		2.38	1.61	2.14	1.68
15. There is no way we can possibly keep _____ in our house.	1 , 2	5.76	.85	5.96	.21
		6.00	.00	5.92	.28
		5.18	1.60	6.00	.00
		5.85	.38	6.00	.00
16. We take _____ along when we go out.	5 , 6	2.27	1.39	2.00	.95
		2.59	1.59	2.00	.91
		1.91	1.04	1.67	1.15
		2.00	1.21	2.14	1.07
17. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.	5 , 6	2.02	1.71	2.29	1.87
		2.50	2.09	2.83	2.21
		1.73	1.56	1.00	.00
		1.46	.66	1.83	1.17
18. _____ is better off in our home than somewhere else.	5 , 6	1.50	1.21	1.26	.69
		1.23	.75	1.15	.55
		1.91	1.58	1.00	.00
		1.62	1.45	1.57	.98

Table 4. Stress Questionnaire Adapted (Kronenberger and Thompson 1990)
Comparison of means on the Stress Questionnaire from the first time to the second time the scale was completed by Level of Care.

Not at all Stressful — Somewhat — Extremely Stressful
1 2 3 4 5 6 7

Item	Time 1 Overall n = 47 LOC 1 n = 22 LOC 2 n = 25 x SD	Time 2 Overall n = 23 LOC 1 n = 10 LOC 2 n = 13 x SD
1. Dealing with the medical problems associated with my child's illness.	5.49 1.57 5.45 1.60 5.52 1.58	5.13 1.25 5.30 1.34 5.00 1.22
2. Maintaining my child's emotional stability.	3.23 1.87 3.23 2.05 3.24 1.74	3.04 1.61 3.60 1.78 2.62 1.39
3. Helping my child maintain an adequate level of school performance.	3.35 2.10 2.90 2.07 3.74 2.09	3.40 2.14 4.00 2.29 2.91 1.97
4. Dealing with other major crises in my life (excluding those of my child).	4.49 1.74 4.36 1.47 4.60 1.98	4.17 1.47 4.10 1.37 4.23 1.59
5. Maintaining my emotional stability when facing stress related to my child's illness.	4.74 1.69 4.68 1.78 4.80 1.63	4.39 1.59 5.00 1.49 3.92 1.55
6. Maintaining my emotional stability regardless of the stress of my child's illness.	3.66 1.81 3.68 1.81 3.64 1.85	3.87 1.60 4.50 1.58 3.38 1.50
7. Handling daily tasks in my life (household chores, work, etc.).	3.49 1.47 3.41 1.26 3.56 1.66	3.43 1.59 4.00 1.33 3.00 1.68
8. Maintaining family harmony.	3.51 1.65 3.50 1.50 3.52 1.81	3.52 1.65 4.20 1.48 3.00 1.63
9. Maintaining marital harmony.	3.31 1.87 3.27 1.72 3.35 2.04	3.09 1.57 3.30 1.42 2.92 1.73
10. Interactions with friends and relatives.	2.94 1.58 2.95 1.25 2.92 1.85	2.96 1.66 3.10 1.66 2.85 1.72

Table 5. Stress Questionnaire Adapted (Kronenberger and Thompson 1990)
Comparison of means on the Stress Questionnaire from the first time to the second time the scale was completed by the age of the child.

Not at all Stressful 1 2 3 — Somewhat 4 5 6 — Extremely Stressful 7

Item	Time 1 Overall n = 47 B - 2 n = 22 3 - 5 n = 11 6 - 8 n = 14		Time 2 Overall n = 23 B - 2 n = 13 3 -5 n = 3 6 - 8 n = 7	
	x	SD	x	SD
1. Dealing with the medical problems associated with my child's illness.	5.49	1.57	5.13	1.25
	5.23	1.93	5.23	1.59
	5.82	1.25	5.00	1.00
	5.64	1.15	5.00	.58
2. Maintaining my child's emotional stability.	3.23	1.87	3.04	1.61
	3.23	2.16	3.15	1.52
	3.82	1.60	4.33	2.08
	2.79	1.53	2.29	1.38
3. Helping my child maintain an adequate level of school performance.	3.35	2.10	3.40	2.14
	2.42	2.14	3.20	2.30
	4.20	1.75	4.00	1.73
	4.00	1.88	3.43	2.30
4. Dealing with other major crises in my life (excluding those of my child).	4.49	1.74	4.17	1.47
	4.27	1.86	4.00	.91
	5.09	1.58	5.67	2.31
	4.36	1.70	3.86	1.77
5. Maintaining my emotional stability when facing stress related to my child's illness.	4.74	1.69	4.39	1.59
	4.68	1.86	4.15	1.52
	4.73	1.62	6.00	1.73
	4.86	1.56	4.14	1.46
6. Maintaining my emotional stability regardless of the stress of my child's illness.	3.67	1.81	3.87	1.60
	3.32	1.70	3.70	1.49
	4.00	2.05	6.00	1.73
	3.93	1.82	3.29	1.11
7. Handling daily tasks in my life (household chores, work, etc.).	3.49	1.47	3.43	1.59
	3.68	1.62	3.08	1.32
	3.27	1.62	5.67	1.15
	3.36	1.15	3.14	1.57
8. Maintaining family harmony.	3.51	1.65	3.52	1.65
	3.55	1.47	3.23	1.30
	3.55	1.97	6.00	1.00
	3.43	1.79	3.00	1.63
9. Maintaining marital harmony.	3.31	1.87	3.09	1.57
	3.38	1.80	3.08	1.32
	3.45	2.34	5.00	2.83
	3.08	1.66	2.57	1.51
10. Interactions with friends and relatives.	2.94	1.58	2.96	1.66
	2.77	1.48	2.62	1.26
	3.09	1.97	6.00	.00
	3.07	1.49	2.29	1.25

Table 6. Family Focused Intervention Scale, Resource Assistance (Mahoney, unpublished)
Comparison of means on the survey from the first time to the second time the scale was completed by the Level of Care required by the child.
1 - Not at all adequate, 2 - Seldom Adequate, 3 - Sometimes Adequate, 4 - Usually Adequate, 5 - Almost Always Adequate

Item	Time 1 Overall n = 44 LOC 1 n = 21 LOC 2 n = 23 x SD	Time 2 Overall n = 23 LOC 1 n = 10 LOC 2 n = 13 x SD
1. Money to pay monthly bills.	3.36 1.28 3.32 1.17 3.40 1.38	3.74 1.14 3.80 1.23 3.69 1.11
2. Good job for your spouse/partner.	3.57 1.44 3.62 1.60 3.52 1.31	3.95 1.21 3.60 1.58 4.25 .75
3. Medical care for your family.	3.94 1.36 3.60 1.44 4.24 1.23	4.00 .90 3.60 1.17 4.31 .48
4. Dependable transportation (own car or provided by others).	4.32 1.04 4.18 1.22 4.44 .87	4.43 .66 4.60 .52 4.31 .75
5. Time to get enough sleep/rest.	2.70 1.06 2.59 1.14 2.80 1.00	2.91 1.12 2.90 1.37 2.92 .95
6. Time to be by yourself.	2.17 1.00 2.18 1.10 2.16 .94	2.35 1.15 2.40 1.26 2.31 1.11
7. Time for family to be together.	3.15 1.16 3.00 1.27 3.28 1.06	3.74 1.05 3.50 1.35 3.92 .76
8. Time to be with your child(ren).	3.51 1.32 3.27 1.45 3.72 1.17	4.00 1.17 4.30 1.25 3.77 1.09
9. Time to be with spouse/partner.	2.50 1.07 2.32 1.13 2.67 1.01	2.82 1.14 2.90 1.52 2.75 .75
10. Time to be with close friend (s).	2.28 1.04 2.45 1.26 2.12 .78	2.57 1.12 3.00 1.25 2.23 .93
11. Telephone or access to a phone.	4.53 .95 4.59 .96 4.48 .96	4.74 .75 4.90 .32 4.62 .96
12. Baby-sitting for your child(ren).	3.50 1.17 3.19 1.21 3.76 1.09	3.57 .90 3.60 .97 3.54 .88
13. Child care / day care for your child(ren).	2.98 1.69 2.48 1.78 2.48 1.47	3.24 1.48 2.90 1.45 3.55 1.51
14. Money to buy special equipment or supplies for children.	2.78 1.33 2.73 1.39 2.83 1.30	3.45 1.01 3.20 1.03 3.67 .98

15. Toys for your child(ren).	3.59	1.18	3.78	1.00
	3.45	1.18	4.00	.67
	3.71	1.20	3.62	1.19
16. Money to buy things for yourself.	2.59	1.18	2.87	1.14
	2.73	1.20	2.90	1.10
	2.46	1.18	2.85	1.21
17. Money for family entertainment.	2.55	1.12	2.87	.97
	2.55	1.10	2.80	.79
	2.56	1.16	2.92	1.12
18. Time and money for travel/vacation.	2.04	1.04	2.26	1.25
	2.14	.99	2.10	1.10
	1.96	1.10	2.38	1.39

Table 7. Family Focused Intervention Scale, Resource Assistance (Mahoney, unpublished)
Comparison of means on the survey from the first time to the second time the scale was completed by the age of the child. 1 - Not at all adequate, 2 - Seldom Adequate, 3 - Sometimes Adequate, 4 - Usually Adequate, 5 - Almost Always Adequate

Item	Time 1 n = 47 B - 2 n = 22 3 - 5 n = 11 6 - 8 n = 14		Time 2 n = 23 B - 2 n = 13 3 - 5 n = 3 6 - 8 n = 7	
	x	SD	x	SD
1. Money to pay monthly bills.	3.36	1.28	3.74	1.14
	3.09	1.41	3.77	1.01
	3.45	1.29	2.33	1.53
	3.71	.99	4.29	.76
2. Good job for your spouse/partner.	3.57	1.44	3.95	1.21
	3.55	1.57	4.15	.69
	3.44	1.51	2.00	1.41
	3.70	1.25	4.14	1.57
3. Medical care for your family.	3.94	1.36	4.00	.90
	4.04	1.40	4.08	.49
	3.73	1.62	3.33	2.08
	3.93	1.14	4.14	.90
4. Dependable transportation (own car or provided by others).	4.32	1.04	4.43	.66
	4.27	1.03	4.31	.75
	4.45	1.04	4.67	.58
	4.29	1.14	4.57	.53
5. Time to get enough sleep/rest.	2.70	1.06	2.91	1.12
	2.59	1.01	2.92	1.32
	2.82	1.33	2.00	.00
	2.79	.97	3.29	.76
6. Time to be by yourself.	2.17	1.01	2.35	1.15
	2.05	.79	2.46	1.33
	2.64	1.29	1.00	.00
	2.00	1.04	2.71	.49
7. Time for family to be together.	3.15	1.16	3.74	1.05
	3.05	1.17	3.62	1.12
	3.36	1.50	3.33	1.15
	3.14	.86	4.14	.90
8. Time to be with your child(ren).	3.51	1.32	4.00	1.17
	3.64	1.33	4.15	1.28
	3.00	1.61	3.33	1.15
	3.71	.99	4.00	1.00
9. Time to be with spouse/partner.	2.50	1.07	2.82	1.14
	2.60	1.10	2.85	.99
	2.40	1.51	3.00	1.41
	2.43	.65	2.71	1.50
10. Time to be with close friend(s).	2.28	1.04	2.57	1.12
	2.00	.76	2.54	1.12
	2.82	1.40	1.33	.58
	2.29	.99	3.14	.90
11. Telephone or access to a phone.	4.53	.95	4.74	.75
	4.64	.95	4.54	.97
	4.64	.67	5.00	.00
	4.29	1.14	5.00	.00

12. Baby-sitting for your child(ren)	3.50	1.17	3.57	.90
	3.43	1.16	3.46	.88
	3.82	1.08	3.33	1.15
	3.36	1.28	3.86	.90
13. Child care / day care for your child(ren).	2.98	1.69	3.24	1.48
	2.71	1.85	2.92	1.44
	3.20	1.93	3.33	2.08
	3.27	1.10	3.83	1.33
14. Money to buy special equipment or supplies for children.	2.78	1.33	3.45	1.01
	3.00	1.41	3.67	.65
	2.80	1.40	2.00	1.00
	2.43	1.16	3.71	1.11
15. Toys for your child(ren).	3.59	1.18	3.78	1.00
	3.57	1.03	3.69	1.18
	3.09	1.64	3.33	1.15
	4.00	.88	4.14	.38
16. Money to buy things for yourself.	2.59	1.18	2.87	1.14
	2.33	1.11	2.69	.95
	2.73	1.49	1.67	1.15
	2.86	1.03	3.71	.95
17. Money for family entertainment.	2.55	1.12	2.87	.97
	2.36	1.09	2.69	.95
	2.91	1.45	2.33	.58
	2.57	.85	3.43	.98
18. Time and money for travel/vacation.	2.04	1.04	2.26	1.25
	1.91	.97	1.92	1.11
	2.45	1.29	1.67	1.15
	1.93	.92	3.14	1.21

Table 8. Parent Satisfaction Survey (n=63)
Time 1 (n=39) Time 2 (n = 19)(1 - Strongly Disagree , 2 - Disagree, 3 - Agree, 4 - Strongly Agree)

Item	Overall		Time 1		Time 2	
	x	SD	x	SD	x	SD
Program and Staff Responsiveness						
1. PPCS staff listen and respond to my concerns, questions, and ideas	3.57	.530	3.59	.549	3.58	.507
2. In my meetings with PPCS staff (for assessments, conferences, monthly updates, etc.) I feel I am an active member of the team and not just a listener.	3.48	.564	3.49	.601	3.37	.496
3. Although one staff member from PPCS mainly serves my child, I feel that we receive the expertise of other PPCS staff.	3.13	.582	3.23	.536	2.84	.602
4. PPCS staff give me information that is clear and useful to me.	3.51	.535	3.54	.505	3.37	.505
5. I feel the services provided through the PPCS program include what is important to me.	3.49	.535	3.56	.502	3.26	.562
6. My family's services through PPCS meet my family's needs.	3.37	604	3.44	.598	3.21	.630
7. The help my family is getting is based on our individual needs.	3.57	.530	3.62	.544	3.42	.507
8. I am satisfied with my community service providers since beginning this program.	3.54	.618	3.64	.584	3.37	.684
9. The help I get fits into our family routines and activities.	3.41	.557	3.54	.505	3.16	.602
10. PPCS staff respect the limits my family puts on our time and energy.	3.41	.496	3.49	.506	3.26	.452
11. I am informed of a variety of choices for how my child could be served.	3.33	.648	3.44	.641	3.11	.658
12. I feel PPCS staff give me state of the art information. (e.g., laws, educational and medical practices, funding, and equipment).	3.29	.671	3.34	.725	3.16	.602
Utilization of Community Services Because of my participation with PPCS services:						
13. I know more about community agencies, services, and programs that can help my child or my family.	3.21	.699	3.26	.637	2.95	.780
14. I get help from PPCS staff when I want other programs or people to work with me, my child, or my family.	3.27	.627	3.26	.677	3.26	.562
15. I now have contact with services and programs in the community who may help my child or my family.	3.27	.677	3.21	.767	3.26	.452
16. I am satisfied with the communication between my child's team and community resource persons involved in my child's program.	3.35	.546	3.41	.549	3.22	.548
17. I am able to get information that is important to the health and happiness of my family and child.	3.37	.548	3.38	.544	3.21	.535
18. I have been able to spend more time with my spouse or family because of receiving respite services.	3.31	.856	3.31	.867	3.26	.933
19. I have been able to arrange respite care by a qualified person.	3.39	.851	3.40	.914	3.42	.769
20. I have been able to arrange respite care for my child on a dependable schedule.	3.15	.906	3.23	.910	3.00	.943

Building a Support System Because of my participation with PPCS services:						
21. PPCS staff helped the people I know be more caring and understanding of my child.	2.86	.780	2.95	.759	2.74	.806
22. PPCS staff helped me get to know other people who are caring and understanding	3.12	.640	3.03	.707	3.00	.594
23. I have gotten support from other parents.	2.53	.947	2.49	1.027	2.50	.786
24. I feel less alone as the parent of my child.	2.93	.834	2.84	.886	3.06	.725
25. PPCS staff are willing and able to help my family and friends when we have concerns or questions about my child.	3.40	.527	3.46	.555	3.32	.478

Table 9. Respite Training Program Evaluation (n = 177)

5 Strongly Agree	4 Agree	3 No Opinion	2 Disagree	1 Strongly Disagree

Item	Mean	S. D.
The information given in this Training Session will help me do my job more completely.	4.69	.574
The skills taught in this Training Session were skills I needed to do my job more completely.	4.56	.629
Because of this Training Session I have gained more knowledge about the Respite Program Requirements.	4.72	.571
The methods used for teaching this Training Session were effective for me to learn by.	4.46	.665
The instructor communicates effectively and enthusiastically.	4.75	.655
I was given an opportunity to ask questions.	4.79	.630
My questions were answered in an understandable way.	4.74	.731

Table 10. Respite Provider Training Survey (n = 15)
Items were rated on a scale from 1 to 7; 7 being the favorable or positive end of the continuum and 1 reflecting the negative or no impact.

Item	Mean	S D
Respite Training Course		
1. How would you rate the amount of information you received during the Respite Training Course?	6.40	1.121
2. How would you rate the helpfulness of the Respite Training Course in performing the job you now do?	5.27	1.486
3. How much did attending our Respite Training Course increase your knowledge of working with individuals who have medical needs?	5.13	1.727
4. How much did attending our Respite Training Course increase your skills in working with individuals who have medical needs?	4.93	1.624
5. To what degree has your attitude changed in respect to working with individuals who have medical needs as a result of our Respite Training Course?	5.20	1.474
In-Home Hands-On Training From PPCS Staff		
6. How would you rate the amount of training assistance you received during the In-Home Hands-On Training?	5.20	1.699
7. How would you rate the helpfulness of the In-Home Hands-On Training in performing the job you now do?	5.60	1.882
8. How much did the In-Home Hands-On Training you received increase your knowledge in working with individuals who have medical needs?	5.13	1.885
9. How much did the In-Home Hands-On Training you received increase your skills in working with individuals who have medical needs?	5.07	1.907
10. To what degree has your attitude changed in respect to working with individuals who have medical needs as a result of the In-Home Hands-On Training?	5.27	1.534
Ongoing Assistance In The Home From PPCS Staff		
11. How would you rate the amount of training assistance you received since you have been in the home?	4.47	2.100
12. How would you rate the helpfulness of assistance you have received since you have been in the home?	4.60	2.261
13. How much has the assistance you have received since you have been in the home increased your knowledge of working with individuals who have medical needs.	4.133	1.995
14. How much has the assistance you have received since you have been in the home increased your skills in working with individuals who have medical needs?	4.27	2.120
15. To what degree has your attitude changed in respect to working with individuals who have medical needs as a result of the assistance you have received since you have been in the home?	4.33	1.915
General Questions		
How would you rate the enjoyment of the job you now perform?	6.20	1.821
How would you rate your confidence (comfort) level in doing your job based on the assistance you have received from PPCS staff?	5.53	1.807

Table 11. Patterns in individual health. Overall means by month by year.

Doctor Visits

Month		1994			1995			1996	
	n	x	S.D.	n	x	S.D.	n	x	S.D.
January				17	.65	1.06	51	.51	.784
February				23	1.30	1.74	63	.59	.587
March	6	.33	.516	20	1.80	2.57	51	.92	1.111
April	13	.62	1.193	59	1.22	1.54	44	1.09	1.254
May	9	.33	.500	49	1.18	1.75	30	1.23	1.357
June	6	.17	.408	75	.73	1.08	18	1.11	1.450
July	8	.63	1.061	59	.41	.72	10	.50	.527
August	16	1.38	3.575	45	.62	1.13			
September	24	1.50	3.349	51	.80	1.02			
October	24	1.46	2.085	52	.75	1.10			
November	23	2.17	5.015	55	.62	1.06			
December	29	1.76	2.340	65	.55	1.12			
Overall	158	1.35	2.923	570	.82	1.32	267	.82	1.077

Trips to the Emergency Room

Month		1994			1995			1996	
	n	x	S.D.	n	x	S.D.	n	x	S.D.
January				17	.12	.332	51	.00	.000
February				23	.13	.344	63	.06	.246
March	6	.17	.408	20	.10	.308	51	.08	.272
April	13	.08	.277	59	.02	.130	44	.09	.362
May	9	.00	.000	49	.10	.368	30	.10	.305
June	6	.00	.000	75	.03	.162	18	.22	.428
July	8	.00	.000	59	.08	.314	10	.00	.000
August	16	.75	2.490	45	.02	.149			
September	24	.08	.282	51	.08	.440			
October	24	.13	.448	52	.02	.139			
November	23	.09	.288	55	.04	.189			
December	29	.17	.658	65	.03	.174			
Overall	158	.16	.880	570	.05	.257	267	.07	.272

Hospitalization

Month		1994			1995			1996	
	n	x	S.D.	n	x	S.D.	n	x	S.D.
January				17	.18	.393	51	1.00	4.142
February				23	.13	.344	63	.48	2.039
March	6	.33	.816	20	.30	.571	51	.61	2.145
April	13	.08	.277	59	.22	.872	44	.45	2.444
May	9	.00	.000	49	.39	1.239	30	.30	1.208
June	6	5.83	12.432	75	.15	.630	18	.56	1.917
July	8	.00	.000	59	.07	.365	10	.00	.000
August	16	.69	2.496	45	.49	2.710			
September	24	.25	.737	51	.02	.140			
October	24	.17	.816	52	.10	.693			
November	23	.43	1.471	55	.20	1.026			
December	29	.21	.675	65	.29	1.998			
Overall	158	.47	2.699	570	.21	1.213	267	.57	2.546

Days of illness

Month		1994			1995			1996	
	n	x	S.D.	n	x	S.D.	n	x	S.D.
January				17	3.88	11.384	51	1.02	4.150
February				23	1.52	6.295	63	.48	1.318
March	6	.83	2.041	20	1.20	2.840	51	.33	.589
April	13	1.08	2.900	59	.81	2.603	44	.91	2.550
May	9	.44	1.333	49	2.00	6.991	30	1.03	2.266
June	6	.00	.000	75	.81	1.828	18	.83	1.978
July	8	.00	.000	59	.17	.562	10	.80	1.476
August	16	1.62	3.222	45	.20	.786			
September	24	3.25	9.023	51	.33	.712			
October	24	.29	1.429	52	.73	2.482			
November	23	2.04	3.784	55	.60	2.033			
December	29	1.14	2.279	65	.63	2.336			
Overall	158	1.35	4.249	570	.84	3.593	267	.72	2.392

Table 12. Overall means of health status divided by age category.

Doctor visits		1995			1996	
Age	n	x	S.D.	n	x	S.D.
Birth - 2 years	218	1.14	1.589	124	1.10	1.136
3 - 5 years	162	.79	1.258	48	.77	1.207
6 - 8 years	190	.46	.846	95	.49	.810

Emergency Room		1995			1996	
Age	n	x	S.D.	n	x	S.D.
Birth - 2 years	218	.08	.33	124	.15	.376
3 - 5 years	162	.02	.16	48	.00	.000
6 - 8 years	190	.04	.23	95	.10	.103

Days of illness		1995			1996	
Age	n	x	S.D.	n	x	S.D.
Birth - 2 years	218	1.58	5.462	124	1.07	3.201
3 - 5 years	162	.63	1.828	48	.33	.907
6 - 8 years	190	.17	.801	95	.46	1.435

Statement of Future Activities

The Personalized Pediatric Coordinated Services (PPCS) Model will continue to be used in the Community Services Department of the Hattie Larlham Foundation. The PPCS model will also be utilized at Health Hill Hospital for Children. Dissemination of PPCS project findings will continue and technical assistance will be provided to replication sites as per their request. A publisher is being sought for two of the articles written by project staff and PPCS Model products will be available for the public.

Hattie Larlham Foundation

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The Children Are The Reason

December 18, 1996

Ms. Mary Vest
Office of Special Education Programs
U.S. Department of Education
400 Maryland Avenue SW
Switzer Building Room 3516
Washington, DC 20202-2626

Dear Ms. Vest;

Enclosed are three copies of our full and final report of the Personalized Pediatric Coordinated Services Grant, Grant number FR-AWARD H024B10079-95.

We have mailed one full and final report to Eric. Also sent were copies of the title page and abstract to:

NEC*TAS

National Clearinghouse for Professions in Special Education

National Information Center for Children and Youth with Disabilities (NICHCY)

Technical Assistance for Parent Programs Project (TAPP)

National Diffusion Network

Child and Adolescent Service System Program (CASSP)

Northeast Regional Resource Center

MidSouth Regional Resource Center

South Atlantic Regional Resource Center

Great Lakes Area Regional Resource Center

Mountain Plains Regional Resource Center

Western Regional Resource Center

Federal Regional Resource Center

If you have any questions or concerns, please feel free to contact me at 1-800-551-2658.

Sincerely,

Gary Schultz, R.N., M.A.
Project Director

GS/klb

Enclosure

APPENDIX

PPCS Management Plan. Year I - III.

PPCS Management Plan. Year IV and V.

Outside Evaluator Review of the PPCS Project.

MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 1. Operate a Personalized Pediatric Coordination Services Program for children with complex medical needs (from birth to five years of age) and their families.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.6 Establish a Quality Assurance Committee comprised of at least (a) a board–certified pediatrician families with PPC services, (b) a registered nurse with acute pediatric experience, (c) a consumer representative (d) developmentalist or education specialist, (e) social worker.	Gibson/Kulasa	Month: 1 YR 1 As needed YR 2 " YR 3 " YR 4 " YR 5	3/20/92	The Advisory Board is comprised of the necessary members for the QA Committee and serves in both capacities.	The same Q.A. committee will continue to be used for Year II.
1.7 Continue to schedule and conduct quarterly Advisory Board meeting with the PPCS Advisory Board that has been meeting monthly since February 1989.	Gibson/Kulasa	Month: 1,4,7,10 YR 1 13,16,19,22 YR 2 25,28,31,34 YR 3	On–going through Sept. 1994	12/5/91, 3/4/92, 6/3/92, 9/2/92, 12/3/92, 3/18/93, 9/16/93.	Advisory Brd will be moved to biannually unless we have the need for a special meeting. Effective September 1993. In September 1993 board decided it would not meet again until after site visit in May.
1.8 Write and implement Policies and Procedures pertaining to all PPCS Program and revise as needed.	Kulasa/McPeake	Month: 1,2 YR 1 As needed YR 2 " YR 3	On–going through Sept. 1994	Beeper Policy For Respite Program Equipment/Seminar Request Policy Respite Definitions Respite Per Diem and Payment Parameters In – Home Community Alternatives Respite Incident Report Guidelines Employee Orientation Training PPCS Waiting List Guidelines Community Alternatives Waivers Training Guidelines Unusual Incident Policy Reporting and Inivestigation of Alleged Instances of Abuse, Neglect, or Mistreatment Client Preference/Choice Survey Department program policies being reviewed Met 1/21/93, 2/4/93, 3/17/93, 3/31/93, 5/4/93, 5/14/93. Respite training being revised. Met 5/14, 6/7, 6/24; 7/15/93. Beeper Policy Revised 7/30/93. Respite Medication Policy 6/93 Transition Policy 10/93. Beeper Policy Revised 12/93.	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 2. Infants and children considered for admission to the PPCS Program will be those with complex health care needs from birth to five years of age and their families.

ACTIVITIES	PERSON RESPONSIBLE	GRAN TIMELIN	COMPLETION DAT	PROGRESS TO DATE	COMMENTS
2.1 All PPCS referrals will be processed through the Hattie Larlham Foundation's Admissions Committee which meets on a monthly basis.	Kulasa/Duffield	As needed	On-going through Sept. 1994	Admission meetings: 10/02/91, 1/15/92, 1/29/92, 2/26/92, 3/11/92, 3/25/92, 4/8/92, 4/29/92, 5/20/92, 6/3/92, 6/17/92, 7/1/92, 8/5/92, 9/17/92, 10/28/92, 11/11/92, 11/25/92, 12/16/92, 12/28/92; 1/13/93; 1/27/93, 2/10/93 2/24/93, 3/10/93; 4/16/93; 5/12/93, 6/10/93, 6/14/93, 6/30/93, 7/26/93, 9/20/93, 10/19/93, 11/3/93, 11/24/93,	HLF Admissions Committee meets monthly. Policies revised 11/93.
2.2 Work with children in the PPCS Project who can benefit from the program services.	Program Staff/CHP's	Month: 1 – 12 YR 1 13 – 24 YR 2 25 – 36 YR 3	On-going through Sept. 1994	47 Active, 12 Closed; 59 Total over 1st grant year. Month 4, Year II 46 active. Month 5, year II, 47 active Month 6 Year II, 45 active Month 7, Year II, 50 active Month 8, Year II, 38 active Month 9, Year II, 41 active Month 10, Year II, 43 active Month 11, Year II, 45 active Month 12, Year II, 47 active Month 1, Year III, 46 active Month 2, Year III, 46 active Month 3, Year III, 44 active	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 2. Infants and children considered for admission to the PPCS Program will be those with complex health care needs from birth to five years of age and their families.

ACTIVITIES	PERSON RESPONSIBLE	PLAN TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.3 Conduct an intake meeting with the child and family in the child's home or parents' place of preference (i.e., FCLC).	Program Staff, Parent guardian/relevant agency repres.	Month:1 – 12 YR. 1 13 – 24 YR. 2 25 – 36 YR. 3	On-Going through Sept. 1994	On-Going basis	
2.4 Have parent/guardian sign all necessary consent forms, enrollment paperwork prior to having the child receive program services.	Program Staff Administrative Assistant	Month:1 – 12 YR. 1 13 – 24 YR. 2 25 – 36 YR. 3	On-Going through Sept. 1994	We have information releases signed on the first home visit. If the family wishes to participate in the evaluation study we have those forms signed as well during the first visit. Evaluation study forms were revised and condensed in month 4, year II. In month 5, year II most study participants received study forms for the 6 mos. participation point. Month 6, Year II, 30 study participants – 3 new this month. Month 7, Year II, 30 study participants – 1 new this month, 1 dropped. Month 8, year II, 28 study participants – two dropped out. Month 9, year II, 27 study participants, 1 dropped out. Month 10, year II, 26 study participants, 1 dropped out. Month 11, Year II, 24 study participants Month 12, Year II, 24 study participants Month 1, Year III, 24 study participants Month 2, Year III, 24 study participants Month 3, Year III, 26 study participants	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 3. An Individual Family Service Plan (IFSP) or IHP/IEP specific to the developmental and medical needs of the child and the goals identified by the family will be written with measurable goals and a description of the child's and family's strengths and performance level with respect to each goal.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Conduct a functional assessment in the areas of self-care skills, motor skills, language development, growth and developmental social skills.	Program staff/ Community Provider	Month:1–12 YR 1 13–24 YR 2 25–36 YR 3	On-going through Sept. 1994	We do not conduct the assessments through this program but access the families to programs that do and receive the information Year II, month four functional assessment forms developed based on IFSP and distributed to service coordinators to incorporate into the family information report and interview.	We are revising programs to do functional assesment utilized on IFSP. Functional Assessment form developed 2/93. Final IFSP version developed 6/93.
3.2 Develop a protocol for care that will specify the treatment plan needed to accommodate the medical, nursing, psychological and educational needs of the child and family. This care plan will follow the Individualized Family Service Plan (IFSP) format (or IHP/IEP format).	Kulasa/IFSP Team	Month:1–12 YR 1 13–24 YR 2 25–36 YR 3	On-going through Sept. 1994	New in Year II, month 4: Project coordinator appointed to Summit Co. committee to develop IFSP process. In month 4; 2 IFSP's and 2 IEP's acquired. In month 5, year II, IFSP's and IEP's acquired. We are pilot site for new Summit Co. Interagency IFSP forms 2/93. 5/93 – 2 IEP's on PPCS clients. 9/14/94 – 1 IEP 10/93 – 1 IEP 11/93 – 1 IEP, 11/93 – 2 ISP	We are in the process of working with FCLC and other county agencies to process and/or retrieve copies of all treatment plans for active families. We are involved with development of the IFSP interagency process in Summit Co., Medina, Wayne, Stark, Portage, Cuyahoga.
3.3 Conduct quarterly review of the Individualized Family Service Plan or IHP/IEP and make changes in all Program areas as deemed necessary by the IFSP Team.	Kulasa/IFSP Team	Month: 3,6,9,12, YR 1 15,18,21,24 YR 2 27,30,33,36 YR 3	On-going through Sept. 1994	11/19/91 Meeting with HLF Administration re: what IFSP process means for HLF 1/18/92 requested IFSP from Cuyahoga Co MR/DD (Family) 1/28/92 IEP – E.S. 5/18/92 – Mtg. with FCLC re: IFSP development 8/24/92 – M. Family IFSP (2) 9/22/92 – Mtg. with CHMCA Rehab services Re: IFSP development 9/92 – requested IFSP from Summit MR/DD (F. Family) 10/92 0 received IFSP from Summit MR/DD 12/14/92 – IEP team Mtg. 1 client 12/15/92 – mtg. to discuss IFSP form revisions 2/18/93 mtg. with Summit Co. agencies to develop IFSP Interagency Form. 2/24/93 Mtg. at Blick Clinic re: Summit Co Interagency Assessment Process for IFSP's. 3/4/93, 3/23/93, 4/1/93, 4/8/93, 4/22/93, 5/5/93, 6/8/93, 6/24/93, 7/22/93, 8/19/93, 9/23/93, 10/14/93, 10/26/93, 12/9/93, Summit Co. Interagency IFSP Committee	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 4. Provide access to and/or services and coordination to enable families to use community services through multiple service providers.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIME LINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
4.1 Contract with potential transportation sources when the family/child are in need of such services (i.e., UCPSH, county board).	McPeake/Kulasa	As needed YR 1 • YR 2 • YR 3	On-going through Sept. 1994	9/21/92 MR/DD to provide trans. for 1 family's child in out-of-home respite 9/14-9/21. Transportation issue addressed on Family contact sheet.	
4.2 Coordinate social, medical, health, educational, early intervention services, as needed, and as desired by family.	Kulasa/Program Staff	As needed YR 1 • YR 2 • YR 3	On-Going through Sept. 1994	52 families received service coordination to some degree during the first grant year. Families recieved service coordination to some degree during second grant year. 46 received service coordination in Year II 40 of these were new referrals.	
4.3 Assist the child, the family, and the admitting agency during the transitioning phase.	Kulasa/IFSP/ISP IHP Teams	As needed YR 1 • YR 2 • YR 3	On-Going through Sept. 1994	On-Going	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION I: Program Implementation

GOALS: 5. Modify project methods and procedures on basis of evaluation data.

ACTIVITIES	RESPONSIBLE	TIMELINE	COMPLETION DATE	PROGRESS	COMMENTS
5.1 Evaluate program as delineated in Evaluation Plan and according to project timeline.	Gibson/Kulasa	As needed YR 1 " YR 2 " YR 3	On-going through Sept. 1994	(See monthly management meeting dates) Weekly direct Program, Staff team meetings are also conducted.	Will continue throughtout Year II and for remainder of Grant Period.
5.2 Modify project methods accordingly.	Gibson/Kulasa Program Staff	As needed YR 1 " YR 2 " YR 3	On-Going through Sept. 1994	We have modified our processes as needed through the first year. 12/10/92 – Evaluation mtg. held – eval. study modified accordingly. 1/20/93 – Evaluation study forms revised & in-service given to staff. 2/93 New functional assessment Forms and new home visit forms developed. 2/93 PPCS staff in pilot project for Summit Co. interdisciplinary IFSP project. 3/93 Transition Plan form in place to determine readiness for families to move out of the program. 6/93 – Planning for NEC*TAS visit in Sept 93; planning for state agency meeting in September. 7/93 – Chose Summit Co. IFSP (initial & actual) form for use in all counties where countywide forms are not available. 9/93 – NEC*TAS visit & discussion regarding project evaluation. 9/93 Project eval. conference attended by 1 staff member. 10/93 – Grad assistant to collect data on all study participants no longer receiving active services. 1/94 – Initiated Family Contact Form every 6 months on everybody..	Will continue throughtout Year II and for remainder of Grant Period.

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 6. Recruit and train in-home and out-of-home respite providers and match them with appropriate families.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
6.1 Recruit respite providers in the geographical areas that have an identified need.	Kulasa	As needed YR 1 • YR 2 • YR 3	On-going through Sept. 1994	Respite providers in different counties On-going Recruiter attended job fair in Stark Co. in 1/93 2/8/93 Met w/new nurse respite trainer 7/93 – New respite recruiter hired with dept. 8/93 – New respite recruiter hired with dept. 10/4/93 Respite mtg with Medina Co. to implement EI funds. 11/30/93 Respite Recruiting mtg. Summit Co. (20) 10/93 Nurses' Job Fair 11/24/93 Respite mtg with Wayne & Medina Co. to implement EI funds. 11/9/93 Nursing open house HLF.	Weekly respite mtg. Instituted 9/93 to identify need and monitor progress.

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 6. Recruit and train in-home and out-of-home respite providers and match them with appropriate families.

ACTIVITIES					
6.2 Train all respite providers in all needed areas, including medical training and First Aid/CPR	Kulasa	As needed YR. 1 " YR. 2 " YR. 3	On-going through Sept. 1994	12/3/91 in-home (1) 1/15/92 in-home (1) 1/22/92 in-home (1) 2/26/92 Classroom training module VIII (4) 3/3/92 in-home (1) 3/9/92 in-home (1) 3/18/92 Classroom module VII (5) 3/19/92 in-home (1) 3/20/92 in-home (1) 3/30/92 in-home (1) 4/6/92 in-home (1) 4/24/92 in-home (1) 5/1/92 in-home (2) 5/6/92 in-home (1) 5/7/92 in-hom e(1) 5/7/92 in-home (1) 5/15/92 in-home (1) 5/18/92 in-home (1) 5/21/92 in-home (1) 5/26/92 in-home training (4) 5/28/92 in-home (1) 6/10/92 in-home (1) 6/16/92 in-home (1) 6/25/92 in-home (1) 7/8/92 in-home (1) 7/9/92 in-home (1) 7/9/92 out-of-home (1) 8/24/92 in-home (1) 8/27/92 in-home (1) 9/14/92 out-of-home (1) 9/25/92 in-home (1) 10/6/92 in-home (1) 10/27/92 in-home (1) 10/28/92 classroom training module (5) 11/5/92 in-home (1) 11/10/92 – in-home (1) 11/18/92 respite prov. training (1) 12/7/92 – out-of-home (1) 12/14/92 – in-home (1) 12/21/92 – in-home (1) 12/22/92 – in-home (1) 12/30/92 – in-home (1)	1/5/93 – out of home (1) 1/5/93 – in-home (1) 1/25/93 – Classroom module VII (4) 2/11/93 – in-home (1) 3/8/93 – in-home (1) 3/23/93 – in-home (1) 3/31/93 – out-of-home (1) 4/19/93 – Classroom training (4) 5/10/93 – in-home (1) assess. 5/14/93 – Training modules revisions (3) 5/15/93 – in-home (1) assess. 5/17/93 – in-home (1) assess. 5/19/93 – in-home (1) assess. – in-home (1) assess. 5/25/93 – in-home (2) assess. 6/7/93 – in-home (1) assess. 6/9/93 – in-home (1) assess. 6/11/93 – in-home (1) assess. 6/14/93 – classroom training (2) 6/14/93 – in-home (1) assess. 6/14/93 – assess. (1) 6/17/93 – in-home (1) assess. 6/18/93 – in-home (1) assess. 6/22/93 – in-home (1) assess. 7/22/93 – Classroom module VII (4) 9/93 in-home training (1) 9/13/93 Classroom training (5) 10/93 Classroom training 11/93 Classroom training 12/8/93 Classroom training (3) 12/15/93 Classroom training (5) 12/20/93 Classroom training (4)

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION II: Training

GOALS: 1. Provide comprehensive initial and on-going training to all PPCS staff and service providers.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Conduct orientation training with each new employee to acquaint them with the philosophy, organization, program, practices, and goals of the PPCS program.	Kulasa	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-Going through Sept. 1994	See Orientation Policy. Done as needed with new staff. Met with staff development personnel to review needs of community services Dept. staff 1/93.	MaryJo Sabella has assumed the duties formerly held by Maureen Napoli.
1.2 Offer basic life support (CPR) classes and make certain that all direct service providers maintain their CPR certification.	HLF Comm. Services Dept.	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-going through Sept. 1994	12/5/91 – 12/12/91 six CPR, six First Aid 1/21/92 – 1/28/92 five CPR, four First Aid 2/11/92 – 2/18/92 five CPR, five First Aid 3/10/92 – 3/17/92 three CPR, four First Aid 5/12/92 four CPR, two First Aid 8/92 – four CPR; 9/92 – three CPR 9/92 – three CPR 11/92 – five CPR, one First Aid 12/92 – CPR 1/20/93 – CPR, (8) 1/27/93 – First Aid (8) 2/20/93 – CPR 3/10/93 – CPR (6) 4/7/93 – CPR (4) 4/14/93 – First Aid (3); CPR – Infant/child. 6/16/93 – CPR (4); 6/23/93 – First Aid (4) 7/93 – CPR/First Aid – None 7/93 – Sent reminder of CPR/First Aid Schedule 8/93 – CPR/First Aid – None 9/8/93 – First Aid (7) 9/15/93 – CPR (7) 10/93 – CPR/First aid – None 11/8/93 – CPR/First Aid (8) 12/93 – CPR/First Aid	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 1. Provide comprehensive initial and on-going training to all PPCS staff and service providers.

ACTIVITIES	RESPONSIBLE	GRANT TIMELINE	DATE	TO DATE	COMMENT
1.3 Review infection Control Policy and Procedures and symptoms of communicable diseases.	Kulasa/Bauer	Month: 3,6,9,12, YR 1 15,18,21,24 YR 2 27,30,33,36 YR 3	On-going through Sept. 1994	The project does not have its own policy on infection Control however, we have assisted other agencies to develop and review theirs. 4/14/93 – OSHA Bloodborne Pathogens Project staff immunized against Hepatitis B.	3/30/93 – Visiting Nurse Service Sponsored Strengthening Families (2) 4/2/92 – Genetics conference (1) 4/14/93 – OSHA Bloodborne pathogen (6) 4/21/93 – Inclusion Inservice (2) 4/27/93 – Perinatal Regional conference (1) 4/30/93 – Ventilator update course (1) 5/7/93 Reg. School Nurse Conference – Nurse Practice Law Covered (1)
1.4 Encourage employees and providers to attend workshops or training sessions that will foster growth and enhance skill levels.	Kulasa/McPeake	Month 1 – 12 YR 1 13 – 24 YR 2 25 – 36 YR 3	On-going through Sept. 1994	9/18/91 – I.O Waiver training 11/19/91 – Kent Developmental Metrics (2) November 1991 – March 1992 NCAST Training (1) 1/22/92 NECTAS County Dept. of Human Services 1/29/92 AIDS conference (1) 2/10/92 Play, Art and Music Therapy (1) 3/26/92 BCMH inservice for staff (3) 4/7/92 Setting up Research Practice Sampling (1) 4/22/92 Pediatric Update (2) 4/23/92 Immunization Inservice (2) 5/12/92 EI Sharing Days (3) 5/14/92 Case Managment Inservice (4) 6/1, 6/2/92 Head Start Collaboration (1) 6/9/92 – 6/11/92 NECTAS Denver (3) 12/9/92 – IO Waiver meeting (3) Documentation Inservice (2) 9/23/92 – Cuyahoga County Supported Living Inservice (2) 10/9/92 – Project School Care (4) 10/16/92 – Ohio Coalition For Education 10/21-22/92 – Waiver Case Management meeting (4) 2/10/93 Inservice to Summit Co. board of MR/DD on ventilator and trach dependent pupils. 2/93 Provide information to Summit Co. MR/DD nurse on seizures, oxygen administration. 2/1/93 Inservice given to service Coord. on QRS and PSI instruments. 2/16/93 CPR Training for Staff (1) 2/24/93 – Portage Co SSA Inservice (6) 3/11/93 – Grant Workshop (ODH) (2) 3/12/93 – C.A.F.S. training (2) 3/18/93 – Technology conference (1) 3/25/93 – Positive Outlooks – Residential (2) CONTINUED UNDER COMMENTS	5/10/93 – Fire Safety Inservice (1) 5/12/93 Outcome-oriented Lic. Surveys (1) ODMR/DD 5/19/93 – MEOSERRC Legal Briefs (1) 5/21/93 – Family-Centeredness Training 6/7/93 – Medina County IO Waiver Training (6/17/93 – Family Support Telsconference (1) 6/25/93 – Total Quality Management (2) 6/29/93 – Fire Extinguisher Inservice (1) 7/20/93 – Medical Equip Supplies Inservice on obtaining funding (3). 8/19/93 Total Quality Mng. Conference (3) 8/12-13/93 Sunrise Summer Institute (1) 8/11/93 EPSDT Portage Co. Inservice (2) 9/16/93 Sum. Co. IFSP "Train the Trainers" (2) 9/14-16/93 Midwest Region Project mtg. (1) 10/1/93 ACD Training (1) 10/12/93 Summit Co. IFSP Inservice (1) 10/16/93 Regional CCG Chairperson mtg. (1) 10/14/93 Medina Co. IFSP & Transitions (1) 10/22/93 Developmental Disabilities Neg. (1) 10/22/93 Special Ed. Forum Medina Public schools (1) 10/22/93 Service Coord. mtg. Cuy co. (1) 10/20/93 Ethics Inservice CHMCA (2) 10/21/93 Waivers IV & V training (2) 11/1/93 School Nurse Conference (1) 10/27/93 Interfaith Volunteer caregivers con. (1 11/15-11/16/93 Health Care Reform con. (1) 11/18/93 TEFRA mtg. (2) 12/1/93 Felbamate Drug Inservice (1) 11/24/93 Service Coord. mtg. Sum. Co. (1) 12/7/93 BCMH Update (5)

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 2. Provide comprehensive initial and on-going training to all parents and/or guardian at the time of the child's referral to the PPCS program.

ACTIVITY	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.1 Conduct information session with each new family to acquaint them with the philosophy, services, procedures of the PPCS program.	Kulasa/Program Staff	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-Going through Sept. 1994	52 Families served in first Grant year. 47 Families served in second Grant year.	
2.2 Offer basic life support (CPR) class	Kulasa	Month: 3,6,9,12, YR 1 15,18,21,24 YR 2 27,30,33,36 YR 3	On-going through Sept. 1994	(See CPR Dates) Training offered to Parents & Respite Providers. Also we provide information on area Red Cross agencies that provide training.	
2.3 Assist the family in setting priorities and planning and implementing the child's care at home by (a) improving communication skills to facilitate a collaborative relationship between parents/ guardians and professionsl, (b) orienting them about the IFSP/IHP/IEP process, (c) teaching them hands-on techniques to use in working with their child.	Kulasa/Program Staff/Planning Teams	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-Going through	52 Families served First Grant Year. 47 Families served second Grant year. Family Needs Assessment in family contact study helps families to prioritize their needs. 2/93 Family satisfaction surveys begun to be distributed as part of 6 mos. point study data.	

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FUNCTION II: Training

GOALS: 1. Provide comprehensive initial and on–going training to all PPCS staff and service providers.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.5 Provide training in the implementation new technology.	Kulasa/Bauer	As needed YR 1 • YR 2 • YR 3	On–going through Sept. 1994	nformation provided to families and providers shared on: Passey Muri valve, newer model ventriculo peritoneal shunts, Felbamate anticonvulsant.	

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION II: Training

GOALS: 2. Provide comprehensive initial and on–going training to all parents and/or guardian at the time of the child's referral to the PPCS program.

ACTIVITIES	RESPONSIBILITY	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.4 Increase understanding and coping with the effects of childhood illnesses by offering monthly inservice sessions to families and respite care providers covering a variety of topics, such as (a) issues of death and dying, (b) awareness of services available at the hospital, school, community, state, and professional organizations and (c) fostering advocacy skills.	Kulasa Program Staff	Month: 1–12; YR 1 13–24 YR 2 25–36 YR 3	On–going through Sept. 1994	COMMUNITY SERVICES INSERVICES 10/91 Principles of Discipline (55) attended 11/91 – Open Forum (28) attended 1/92–Agency goals & Programs (10) 2/92–Future Planning & Circle of Friends (24) 3/92–Normal Sibling of Developmental Handicapped Children (14) 6/92–Permancy Planning (22) 7/92–Principles of Abuse and Neglect (14) 10/92 – I.O. billing update (16) 11/92 –Building Foster Family Strengths (10) 12/92 – Letter sent to families regarding Jan inservice. 1/29/93 letter sent out to families in January re: inservices with schedules & maps. 1/17/93 – HLF Administrators on Agency Goals and Programs.(17 attended) 2/93 Inservice on Occupational Therapy 2/93 PPCS Families invited to E.I. Public hearing on 2/24– 1 attended. 4/93 – Letter sent to PPCS families reminding them of upcoming inservices. 4/93 – Physical theraqpy inservice at HLF (4) 5/93 – Speech therapy inservice at HLF (15) 5/93 – Speech technology devices 6/93 Use of play in children with disabilities (13) (13) 9/21/93 Toy lending library Nina Hillery (6) 10/93 Seizures disorders (10) 10/93 letter sent to families requesting testimony of Ohio Health Care Reform.	Families are also informed about local and state inservices that may be of value for them to attend.

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 3. Establish University Graduate Internship Programs in the areas of nursing, education, therapies, and social work.

ACTIVITIES	RESPONSIBLE	TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Contact area universities in order to introduce them to the PPCS Model and services.	Gibson/Kulasa	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-going through Sept. 1994	Preceptorship –grad student through KSU (NSG) Oct 91 –Dec 91 1/22/92 Met with Grad preceptor student (NSG) 2/4/92 KSU undergrad student Inservice (NSG) 2/6/92 KSU undergrad student Inservice (NSG) 2/12/92 KSU grad preceptor student (NSG) 3/11/92 Grad preceptor student (NSG) 9/10/92 contacted by KSU Faculty (NSG) 10/92 University of Minnesota Grad student (Special Education) 11/92 Texas University Grad student (Special Education) 12/92 – 1 Grad student inquired re: internship 3/93 – Approached Akron U. Grad faculty member re: preceptorship for our program. 6/93 – Discussed setting up Community Internship for Medical Residents in Family Practice with Jane Holan., M.D. to begin September 1993. 9/93 – Two KSU Nursing Graduate students in Chronic Illness courses. Met with Akron U. Graduate nurse faculty. 10/93 Two KSU Nursing Graduate students in Chronic Illness courses. Met with Akron U. Graduate nurse faculty. 11/93 November 16 Grantmanship lecture to 6 Graduate nursing students throu University of Akron. 11/93 One family Practice Resident through Akron General four day rotation. 11/93 Presentation to 20 faculty involved in undergrad and grad education of individuals across disciplines (medicine, nursing, nutrition, PT/PTA, OT/OTA, SP/L, ECE, ECSPED, Audiology, Psychology) from universities and colleges of Northern Ohio.	Grant Director teaches Atypical Infant/Newborn Services through KSU.

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION II: Training

GOALS: 3. Establish University Graduate Internship Programs in the areas of nursing, education, therapies, and social work.

ACTIVITIES	RESPONSIBILITY	PLANNED TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.2 Sign affiliation agreements with interested parties in order to establish policies, procedures, and responsibilities.	Allen/Kulasa	Month: 3 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994	1) CHMCA 2) KDM 3) Pip Campbell 1/93 Revised affiliation agreement with KDM & Grad student.	
3.3 Conduct orientation training with all new intern students to acquaint them with the philosophy, organization, program, practices, and goals of the program.	Kulasa	Month: 7 YR 1 15,19 YR 2 27,31 YR 3	On-Going through Sept. 1994	KSU School of NSG was contacted Aug 92 Univ. of Akron Col. of Nurs. contacted Aug 92 Univ. of Akron Col. of Nurs. contacted again in March 93. University of Akron College of Nursing contacted in July 93. Met with Akron College of Nursing faculty regarding student preceptorship Re-contacted Dr. Jane Holan for internship for medical residents on 8/93. 9/20/93 Met with KSU Grad Nsg. Student 11/10/93 Met with 2 KSU Grad. Nsg. Students 11/15/93 Met with 1 Family Practice Resident 12/1/93 Met with 2 Social Work Students from KSU	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 3. Establish University Graduate Internship Programs in the areas of nursing, education, therapies, and social work.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.4 Establish an ongoing training schedule for each student.	Kulasa	Month: 7 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994		
3.5 Schedule and supervise each intern's work through the PPCS Program.	Kulasa/University Staff/Program Staff	Month: 3 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994	Work was scheduled and supervised on an on-going basis by PPCS Coordinator. A letter with suggested agenda for Family Practice interns sent to physician coordinator June 93'. Meeting with Akron University Grad Nsg. Program Faculty 8/20/93. 9/93-12/93 – 2 KSU Graduate nsg students preceptor program. 11/93 1 Family Practice Resident 12/93 2 KSU Social Work students	

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FUNCTION II: Training

GOALS: 4. Provide on-site consultation for community program personnel.

ACTIVITIES	PERSON RESPONSIBLE	PLAN TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
4.1 Consultation and training will be provided to area daycare centers, pre-school programs and integrated education programs.	Kulasa/LPN Gibson	As needed YR 1 • YR 2 • YR 3	On-going through Sept. 1994	10/2/91 First Aid/Safety Head Start Windham (8 attended) 10/20/91 First Aid/ Safety Head Start Kent (20 attended) 1/17/92 Special Needs Advisory Board Head Start, Portage 2/10/92 Infection control & oxygen task inservice to early intervention (10 attended) 3/6/92 OSPRY Evaluation for Portage County Head Start 3/20/92 Portage County Head Start inservice on asthma (20 attended) 5/26/92 FCLC meeting (6 attended) 8/27/92 Emergencies in the Classroom inservice (12 attended) 11/17/92 – Presentation to F. IN. Grief Group at CHMCA 2/10/93 Presented inservice on technology dependent children to Summit Co. MR/DD. 2/10/93 Provided information on seizures and oxygen delivery to Summit Co. MR/DD nurse. 3/16/93 Ohio Early Childhood Conference – PPCS presented (Columbus, Ohio). 3/11/93 Family Child Learning Center – Open House PPCS poster presented. 6/11/93 – IFSP and Service Coordination Inservice – Harrison County 6/16/93 – Service Coordination/IFSP Workshop for EI team Ottawa county. 9/23/93 Infection Control Seminar for FCLC (8). 9/22/93 Presentation to Portage Co. Huamn Services Day Care Providers or children with Complex Medical Needs (15). 12/2/93 Presentation to Graduate Student at FCLC on Institutional Care.	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION II: Training

GOALS: 5. Offer inservice training to interested area agencies, schools, hospitals and professionals.

ACTIVITIES					
5.1 Disseminate information about the PPCS Program's training sessions and make them available to the public.	Gibson/Kuiasa/FCLC Program Staff	Month 1–12 YR 1 13–24 YR 2 25–36 YR 3	On-going through Sept. 1994	9/18/91 PPCS Advisory Board Meeting 10/2/91 Portage LCG 10/10/91 Summit LCG 12/5/91 Advisory Board Meeting 1/23/92 Summit LCG 1/7/92 Portage LCG 1/7/92 Cuyahoga LCG 1/22/92 Summit Co. Human Services Dept. 2/10/92 Advisory Board Meeting 2/14/92 Newsletter 1st Edition 2/17/92 Met with 'Med/Ed.' from North Carolina 2/17/92 Family Journey Conference 2/27/92 Summit LCG 2/28/92 PCPD Meeting 3/4/92 PPCS Advisory Board Meeting 3/6/92 Meeting with Summit Co MR/DD re: respite 3/9/92 Summit LCG 3/12/92 Met with Summit Co intake and referral coordinators 3/16/92 Medina Co MR/DD mtg. 3/30/92 PCPD Meeting 4/1/92 Portage LCG 4/9/92 Parent Education Group inservice Summit LCG 5/1/92 Portage Head Start Special Needs Adv. Bd. Information in three area Resource Manuals 5/28/92 Summit LCG 6/3/92 Advisory Board Meeting 7/29/92 Summit E.I. and Intake and Referral Person 8/92 500 Brochures to PC LCG for dissemination 9/2/92 Advisory Board Mtg. 9/92 Portage Co LCG 9/92 Cuyahoga Co. LCG 9/92 Cuyahoga Co. LCG/9/92 Medina Co. LCG 9/92 Summit Co. LCG 9/16/92 Info given to CHMCA 'Ask – A Nurse' 9/17/92 two Pediatricians Oriented to program. 9/22/92 Met with CHMCA Rehabilitation Services. 9/10/92 Medina Co. Human Services Dept. CONTINUED UNDER COMMENTS	10/7/92 – Portage LCG 10/8/92 – Summit LCG 11/5/92 – Summit Steering Committee 11/12/92 – Medina C. Resource Council 11/11/92 – Portage Co. LCG 11/16/92 Summit Service Coord. 12/3/92 – Summit Service Coord. 12/2/92 – Portage LCG 12/16/92 – Stark LCG 1/12/93 – Medina cluster 1/29/93 – letter sent to families re: HLF inservices as well as Summit Co. ABC inservices. 1/8/93 – E.I. State Procedural Safeguards meeting. 1/14/93 – Summit General Qtly LCG 1/20/93 – Medina Resource council 1/28/93 Cuy. Co. Grant Subcom. mtg. 2/31/93 Portage Co. LCG mtg. 3/4/93 – Summit LCG 3/4/93 – Regional Service Coordination meeting. 3/10/93 – Early Childhood Conference (Columbus, Ohio). 3/11/93 – FCLC Open House – poster presentation. 3/16/93 – Medina Co. Resource Council 3/16/93 – PPCS Quarterly Advisory Board meeting. 3/23/93 – Summit Co. IFSP Committee 3/25/93 – Cuyahoga Co. LCG 3/30/93 – Summit Intake & Referral Committee. 4/1/93 – ABC Steering Committee 4/7/93 – Met with BCMH Task Force 4/16/93 – Stark Co. LCG 4/19/93 – Disabilities Respite Training 4/26/93 – Col. Grad. Course 'A typical infants' lecture medically fragile infants. 4/20/93 – Sum. Co LCG El Confer. presentations on IFSP process. 4/22/93 – Cuyahoga Co. LCG 4/29/93 Regional Perinatal Workshop

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION III: Administration and Management Procedures

GOALS: 1. Determine program costs in order to establish staff/service costs and make certain that the program remains financially solvent.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Design PPCS Program to be a cost-effective alternative to hospital, long-term care facility and in-home nursing care.	Allen/Gibson McPeake	Month: 1 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994	We have participants logging financial data through evaluation study. Evaluation study financial data forms revised to be more user friendly in Jan 1993.	
1.2 Write up yearly operational budget for the program.	Allen/Gibson/ Kulasa/McPeake/ Rubenstein	Month: 1 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994	Done on a yearly basis in conjuction with overall agency yearly operational budget.	
1.3 Approve allowable expenditures for the ongoing operation of the program.	Allen/McPeake Kulasa Rubenstein	Month: 1 YR 1 13 YR 2 26 YR 3	On-going through Sept. 1994	Do on an on-going basis as needs. 4/93 – PPCS Grant audited 5/18/93 – Dept. Dir. & Agency comptroller met to discuss budget; 6/8; 8/3	Janet McPeake now has overall approval for all Department expenses.
1.4 Process necessary reimbursement information and do ongoing fiscal grant documentation and reporting.	Gibson/Kulasa/ McPeake/ Rubenstein	Ongoing	On-going through Sept. 1994	YEAR I 1st quarter, 2/12/92 2nd quarter, 5/12/92 3rd quarter, 8/13/92 4th quarter, 11/12/92 YEAR II 1st quarter, 1/18/93 2nd quarter, 4/16/93 3rd quarter, 7/16/93 4th quarter, 10/18/93 3 Grant budget revisions have been submitted and approved to date 11/91, 7/92, 10/92, 1/11/93, 3/15/93, 6/22/93, 12/23/93	Dianne/Margo/Rubenstein/ McPeake meet on an as needed basis to discuss plan and submit any necessary budget changes, requests, reports. Margo maintains regular contact with federal Fiscal and Grant Officers for the project.

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION III: Administration and Management Procedures

GOALS: 2. Establish reimbursement procedures and mechanisms so that the PPCS program and its services can become financially self-sufficient through public and private third party rembursement options.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.1 Explore potential public reimbursement options, such as, (a) Medicaid State Plan, (b)Medicaid Waivers, (c) Dept. of Mental Retardation/Developmental Disabilities state and county funds.	Allen/McPeake Kulasa	Month 1–12 YR. 1 13–24 YR. 2 25–36 YR. 3	On-going through Sept. 1994	3/16/92 5/14/92 Waiver mtg./Col. 9/23/92 Cuy Co. Supported Living Mtg. 10/21 – 22/92 Waiver mtg./Col. 9/92 – I.O. Waiver Commite 10/92 Waiver IV & V training Work with MR/DD in several counties to utilize Supported Living and Family Resource Funds. 2/10/93 Attended CAFS training in Columbus 3/2/93 Attended Bidder's Conference for Medicaid Waivers in Columbus. 3/93–Medical director met with BCMH, Neg Director 3/19/93 – Telephone confence with ODHS re: Medically Fragile Study bid. 4/7/93 – Team met with BCMH Task Force on Medically Fragile Children 4/9/93 – Grant proposal on medically Fragile Children submitted to ODHS. 4/93 – State Task Force on Service Coordination meeting to discuss funding for service coordination. 5/14/93 – Medically Fragile Grant submitted 6/21/93 – Sent letter to acting chief of MCH regarding funding through BCMH 6/11/93 – Special Options Grants Submitted Wayne, Portage and Medina Counties. – Awarded – 7/9/93 – Local Initiative Grant BEI submitted. – Denied 7/24/93 – EI Grant for County Service Coordination project submitted. – Denied – 8/11/93 – EPSDT Workshop on billing 9/14/93 – HLF awarded Targeted Individual Service Coordination Mtg. 10/93 – Investigated Robert Wood Johnson Foundation Grant for Volunteer Respite providers 11/18/93 Dept. Dir. & Project Coord. met with Chief of Long Term Care, ODHS to discuss TEFRA Funding. 11/22/93 Contacted head of EPSDT at State to discuss reimbursement for case management.	

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION III: Administration and Management Procedures

GOALS: 2. Establish reimbursement procedures and mechanisms so that the PPCS program and its services can become financially self-sufficient through public and private third party reimbursement options.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.2 Explore potential private reimbursement options, such as (a) insurance companies, (b) preferred provider organization (PPO), (c) (HMO) and (d) payment for parents.	McPeake/Kulasa	Month:1 – 12 YR 1 13 – 24 YR 2 25 – 36 YR 3	On-going through Sept. 1994	All potential respite recipents Submit private insurance information to us which in turn is submitted to their insur. co. 2/4/93 Met With CHMCA rep. to discuss funding potential for service coordination through CHMCA clinics by BCMH. 2/8/93 Met with residential facility reps in Richland Co. re: our available services for community clients. 2/11/93 Met with Trumbull Co. residential services. 3/18/93 – Attend Tech Training/Funding Conference sponsored by KSU. 4/93 – Grant Co-Director memeber of Medina Co. LCG task force on respite. 8/4/93 – Teleconference with NEC*TAS to explore continued funding.	
2.3 Continue to apply for federal, state, and local grants and procure private and Foundation donations for equipment services not paid for by public or private party payers.	Gibson/Allen McPeake	Month:1 – 12 YR 1 13 – 24 YR 2 25 – 36 YR 3	On-going through Sept. 1994	ODHS Training Grant Field Initiated Research Grant submitted with Children's Hospital. Local Easter Seals Agencies, Tri-county for Independent Living. BVR resources explored. Explored Services Integration Project (ODHS & BCMH Pilot monies; LCG's additional funds; Family and Children First Initiative monies in 1/93. Explored ODH EI funds – Attended Grant conference 3/11/93. 4/93 – Proposed our Special Options & Local Initiative Grant proposals for ODH E.I. Bureau to 3 counties Portage, Wayne & Medina. Letter to ODH inquing about extra EI funds for fical year 93-94. 5/14/93 Submitted ODHS Med. Fragile Grant Awarded 6/11/93 Submitted Special Opt. E.I. Grant. Awarded 7/9/93 – Submitted Local Initiative Grant. Denied 7/23/93 – Submitted Summit Co E.I. Grant Denied 11/93 Procured private funds through HLF donations for respite. 11/93 Summit Co. respite contract renewed. 1/94 Procured additional private funds for respite.	

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION III: Administration and Management Procedures

GOALS: 2. Establish reimbursement procedures and mechanisms so that the PPCS program and its services can become financially self-sufficient through public and private third party reimbursement options.

ACTIVITIES	PERSON RESPONSIBLE	PLAN TIMELINE	COMPLETION DATE	PROGRESS REPORT	COMMENTS
2.4 Bill public and private third party payers for PPCS Program services not covered by current available resources.	Rubenstein	Month: 1 – 12 YR 1 13 – 24 YR 2 25 – 36 YR 3	On-going through Sept. 1994	All potential respite recipient submit private insurance information to us which in turn is submitted to their insurance co. Services are billed to Waiver recipients according to state guidelines. Counties are billed for respite/equip/home modification needs according to Supported Living and Family Resource guidelines. Respite monies through contract with Summit County. Families have been asked to summit a co-pay for respite services based on their income and their ability to pay. I.O. Waiver is billed to cover Program Specialist costs or each appropriate client.	
2.5 Show financial viability data to demonstrate the PPCS Program's ability to remain financially solvent upon completion of this grant.	Gibson/McPeake Rubenstein	Month: 12 YR 1 24 YR 2 36 YR 3	On-going through Sept. 1994	Local/State resources have been accessed for some direct services that will eventually be used to pay for all direct services to families/children. Departmental tracking of service coordinator's time billable to viable state sources. 2/10/93 PPCS staff attended CAFS training as a potential source of funding. 5/93 4 Grant proposals are in the midst of being sumbitted to fund respite and recruitment & training for respite providers. 7/23/93 – A Grant for Service Coordination in Summit Co. was submitted. – Denied – Department of Community Services which this project is a part of providers percentage of budget.	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION III: Administration and Management Procedures

GOALS: 3. Evaluate the timelines and effectiveness of the project administration and management.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Maintain on-going records of adherence to timelines for completion of all project activities.	Kulasa	On-going	On-going through Sept. 1994	(See monthly management mtg. dates)	Management Plan records maintained.
3.2 Conduct weekly meetings with project staff to review progress and make adjustments as needed.	Kulasa/ Program staff	On-Going – weekly	On-going through Sept. 1994	We meet weekly or every other week depending on need and circumstance.	
3.3 Summarize progress in quarterly reports for the Advisory Board and the Hattie Larlham Board of Trustees.	Kulasa Allen/McPeake	Month: 3,6,9,12, YR 1 15,18,21,24 YR 2 27,30,33,36 YR 3	On-going through Sept. 1994	Board Meetings minutes and statistics are kept on a quarterly basis. 1/24/93, 3/21/93, 5/16/93, 8/22/93, 10/17/93, 12/12/93, 1/24/94.	Departmental statistics are kept monthly including PPCS statistics.
3.4 Summarize progress in annual reports for the Advisory Board and the Hattie Larlham Board of Trustees.	Kulasa McPeake	Month: 12 YR 1 24 YR 2 36 YR 3	On-going through Sept. 1994	Annual report was presented at the 9/92 HLF Board Meeting. 3/8/93 met with HLF Fund Board 3/15/93 met with HLF Board of Trustees	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION IV: Dissemination, Replication and Impact

GOALS: 1. Disseminate information about the PPCS Project to universities, child training programs, hospitals, long-term care facilities, area agencies working with young children and other similar organizations.

ACTIVITIES	RESPONSIBILITY	TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Develop and disseminate newsletter six times yearly to PPCS Program staff, families, area hospitals, agencies, schools and other interested individuals or programs.	Kulasa/Gibson	Month: 3,5,7,9,11 YR 1 13,15,17,19,21,23 YR 2 25,27,29,31,33,35 YR 3 37,39,41,43,45,47 YR 4 49,51,53,55,57,59 YR 5	On-going through Sept. 1996	We have had one newsletter disseminated from the Grant. After re-evaluating this product, we have decided to include information in the Hattie Larlham Foundation's Family Newsletter "The Family Room" which is distributed quarterly and to develop a newsletter dealing with legislation impacting families with medically complex child. Met 8/25/93 about newsletter. Met 9/20/93 about newsletter. 10/25/93 Rough draft submitted 12/17/93. 1/13/94 mtg. to discuss model handbook.	New Project Co-Director will take on responsibility for development of the Grant newsletters for the Grant Period. 88 FCG 88 Boards
1.2 Prepare, print, and disseminate written information about the PPCS Program and services in the form of (a) a brochure, (b) fact sheet, (c) model guide handbook, and (d) Parent Handbook.	Gibson/Kulasa	Month: 1-12 YR 1 13-24 YR 2 25-36 YR 3 37-48 YR 4 49-60 YR 5	On-going through Sept. 1996	2/92 PPCS Brochures 2/14/92 Newsletter 10/1/92 Fact sheet 11/30/92 mtg. re: Parent manual newsletter 12/1/92 mtg 12/15/92 mtg. 12/16/92 mtg. 1/13/93 mtg. 1/20/93 mtg. 2/22/93 mtg. Began to develop Model Hand book. 9/25/93 mtg to discuss Model Handbook 9/20/93 – mtg to discuss Model Handbook. 1/13/94 mtg. to discuss Model Handbook.	Project Co-Director has been hired to oversee development and dissemination of Project Handbooks.

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION IV: Dissemination, Replication and Impact

GOALS: 1. Disseminate information about the PPCS Project to universities, child training programs, hospitals, long-term care facilities, area agencies working with young children and other similar organizations.

ACTIVITIES					
1.3 Present project design and transition methods at local, state, and national workshops and conferences such as DEC, TASH, Professional Association for the Care of Children's Health (ACCH).	Gibson/Kulasa Program Staff	Month: 6–8 YR 1 15–20 YR 2 27–32 YR 3 37–48 YR 4 49–60 YR 5	On-going through Sept. 1996	Information presented at MEOSEPAC sponsored workshop BCMH sponsored regional workshop. 8/23/92. Local presentations are made on a regular basis through area Collaborative Group Workshops. Proposal sent to Ohio DEC to present in March.	We are planning to submit proposals for presentation of Project at the ACCH national workshop.
1.4 Preparation and submission of three articles for publication in journals which focus on Infants and young children, such as, Infants and Young Children, Children's Health Care, and Exceptional Parent Magazine.	Gibson/Kulasa Anderson	Month 25,26 YR 3 38–48 YR 4 49–60 YR 5	On-going through Sept. 1996	2/10/93 – Info presented to Summit Co. MR/DD. 3/16/93 – Presented info at Ohio Early Childhood conference in Columbus. 4/20/93 – Presentation at Summit Co. E.I. Conference. 4/29/93 -- Presentation at Regional Perinatal Conference. 7/13/93 – Poster Presentation at Regional Head Start conference in Birmingham. 10/7/93 Presentation at Division of Early Childhood conference (Regional) Peoria Illinois 11/10/93 Presentation to Stark Co. CCG 11/5/93 Presentation to Northeast Faculty Institute (Regional) 11/16/93 Presentation of Project to Child/Adolescent Nurse Practioner Students.	We plan on writing and starting to submit preliminary reports by the middle of Year III.

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION IV: Dissemination, Replication and Impact

GOALS: 2. Produce and field-test handbooks for use by families and other agencies in and out of Ohio.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.1 Develop a model guide handbook and disseminate to other agencies in and out of Ohio.	Gibson/Kulasa McPeake	Month 6–12 YR 1 18–24 YR 2 30–36 YR 3 42–48 YR 4 54–60 YR 5	On-going through Sept. 1996	11/30/92 – Project Co-Director hired to develop handbook as part of her responsibilities 11/30 – mtg. with coordinator & co-director regarding model handbook 12/1 – mtg. with coordinator & co-director regarding model handbook. 12/15 – mtg. with coodinator & co-director regarding model handbook. 12/16 – mtg. with coordinator & co-director regarding model handbook. 1/20/93 – Mtg with coordinator & co-director regarding model handbook. 2/93 mtg. to begin to write model handbook (coord. and co-director). 5/28/93 – PPCS Retreat-handbooks were discussed. Mtgs. regarding handbook 8/25/93, 9/20/93, 10/13/93	

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FUNCTION IV: Dissemination, Replication and Impact

GOALS: 3. Systematically replicate the model in at least 5 other sites.

ACTIVITIES						COMMENTS
3.1 Evaluate and determine potential replication sites in Ohio and other states.	Gibson/McPeake Kulasa	30–36 37–48 49–60	YR 3 YR 4 YR 5	Ongoing through Sept. 1996	Correspondence with Texas Information sent to Minnesota and Texas Universities re: project Work has been done with Nisonger Center and Easter Seals in Columbus. Cincinnati may be a second Ohio site. 6/4/93 – Teleconference with NEC*TAS to discuss planning meeting in September. 9/7–9/93 Met with NEC*TAS to discuss replication activities. 9/9/93 Met with State Depts. of Educ., MR/DD, B. Akron Childrens Hosp. regarding need to replicate coinciding with State's need for service coordination.	
3.2 Conduct needs assessment and training sessions for replication sites.	Gibson/Anderson Site Coordinator	As needed	YR 4 YR 5	On–going through Sept. 1996	12/20/93 Met with OMR/DD & Governors office on Families & Children First Initiative to discuss replication of project in other Ohio counties. 12/14/93 Met with Tomorrow's Child in Toledo re: replication. 1/94–4/94 On–going meetings with the Medina County Board of MR/DD to become a replication site.	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION V: Evaluation and Research

GOALS: 1. Evaluate the impact of the PPCS Project on (a) hospital readmission data, (b) differences in economic and family stress levels, and (c) developmental progress between children served through the PPCS Program and a matched control group served for by traditional means.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Design and /or approve research studies analyze various program components such as (a) medical aspects, (b) child health and development, (c) family variables and (d) cost comparison studies.	Gibson/Anderson Consultant	Month: 6 YR 1 19 YR 2 31 YR 3 43 YR 4 55 YR 5	On-going through Sept. 1996	3/92 Research Eval. Study begins Research Comm. Meeting 10/18/91, 11/18/91, 1/31/92, 2/7/92, 2/21/92	Research Committee was established to assist with design of the evaluation forms, and overall research process.
1.2 Collate and interpret data to be used for reporting of research findings.	Gibson/Anderson Consultant	Month: 6 YR 1 19 YR 2 31 YR 3 43 YR 4 55 YR 5	On-going through Sept. 1996	7/93 Statistics analyzed for use at DEC/ Head Start Conference in Birmingham, AL 9/93 Statistics analyzed for NEC*TAS consultation. 1/94 Statistics analyzed for Project Director's Mtg. in Washington, DC. 4/94 Statistics analyzed for Continuation Grant Application and Site Review Visit in May.	In July 1992 we contracted with KDM to assist with our data collection, entry and analysis. Data files on the SPSS entry system have been developed for participants. We are in the process of doing preliminary analysis to determine if any changes in the design or implementation of the study are warranted.
1.3 Develop questionnaire to use in analysis of Program Impact.	Gibson/Anderson Consultant	Month 7,8 YR 1 20 YR 2 33 YR 3 44 YR 4 56 YR 5	On-going through Sept. 1996		
1.4 Distribution of questionnaire (plus interview) to staff members and control group to determine perceived benefits and impact for the child and family.	Gibson/Anderson Site Coordinators	Month: 9 YR 1 21 YR 2 33 YR 3 45 YR 4 54 YR 5	On-going through Sept. 1996	Questionnaire is in the process of being developed. Anticipate its completion by 12/92. Distribution and interviews are schedule to begin 1/93.	Preliminary findings indicated that too much paper work is the drawing or choosing not to participate in the study.
1.5 Distribution of questionnaire (plus interview) to staff members and control group agencies/professionals to determine perceived benefits and impact for the child and family.	Gibson/Anderson Site Coordinators	Month: 9 YR 1 21 YR 2 33 YR 3 45 YR 4 54 YR 5	On-going through Sept. 1996	Developed Family Satisfaction Questionnaires in 1/93. Developed Agency Questionaires in 1/93. 2/93 Family Satisfaction Questionnaires begun to be disseminated. 2/93 Agency questionnaires begun to be disseminated. 3/93 – Developed Transition Readiness Scale – begun to be disseminated.	

MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION V: Evaluation and Research

GOALS: 2. Evaluate the effectiveness of project management.

ACTIVITY	PERSON RESPONSIBLE	TIMELINE	COMPLETION DATE	PROGRESS	COMMENTS
2.1 Document the achievement of project goals and compliance to time-table.	Gibson/McPeake Kulasa	Month: 12 YR 1 24 YR 2 36 YR 3 48 YR 4 60 YR 5	On-Going through Sept. 1996	Done monthly.	Monthly Management mtgs. moved to quarterly beginning in March '92.
2.2 Compare actual expenditures for project with budget projections and modify as needed.	Gibson/McPeake Kulasa/Rubenstein	Month: 12 YR 1 24 YR 2 36 YR 3 48 YR 4 60 YR 5	On-Going through Sept. 1996	Done on "as needed" basis by Project Director and Comptroller for federal reporting as well, as agency budgeting reports and planning. 4/93 – Audit on Grant completed by HLF Agency. 5/15/93 – Dept. Dir met with comptroller re: budget; 6/8/93, 8/3/93, 12/93.	

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MANAGEMENT PLAN YEAR I – YEAR III

1994

FUNCTION V: Evaluation and Research

GOALS: 3. Evaluate financial viability and cost–effectiveness of the PPCS Program.

ACTIVITY	RESPONSIBLE	GRAN TIMELIN	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Continue to document and compare health care expenditures for families whose children receive PPCS Program with health expenditures for families whose children did not.	Gibson/Anderson	Month: 12 YR 1 24 YR 2 36 YR 3 48 YR 4 60 YR 5	On–Going through Sept. 1996	Participation in Evaluation study completing expenditures information. 6/93 – 28 families have completed 1st month data; 12 have completed 6 month data and 11 have completed 12 month data. 12/93 33 Families have completed 1st month data; and 19 have completed 6 month data; and 14 have completed 12 month data and 0 for 24 month data.	This appears to be one of the most difficult aspects of data collection for the families. Actual costs are not always given to families by insurance companies, providers or medicaid. We are attempting to simplify the data collection procedures and assist can families in any way we can. Presently, Presently, families report this to be a time consuming, difficult aspects of the study.

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MANAGEMENT PLAN YEAR I – YEAR III

FUNCTION V: Evaluation and Research

GOALS: 4. Evaluate the impact of the project where used in replication sites.

ACTIVITIES	PERSON RESPONSIBLE	PLAN TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
4.1 Evaluation process and instruments and procedures used to determine impact on children, families, and community service providers.	Gibson/Anderson Replication staff Outside Evaluator	Month: 48 YR 4 60 YR 5	On-Going through Sept. 1996	Continue to be analyzed on a regular basis and changes are made as necessary. 6/93 – Planned Evaluation meeting with NEC*TAS 12/93 Contacted Project continuity regarding evaluation of a project through site visit contacted former Med-Ed project for some reason contacted former Project Catch for some research.	

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION I Program Implementation

GOALS 1 Replicate a Personalized Pediatric Coordination Services Program for children with complex medical needs (from birth to five years of age) and their families

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1 1 Establish an advisory team at each site for planning and implementation of site technical assistance plan	Project Director/ Project Coordinator/ Site Coordinator	Month 37-39 YR 4 49-51 Yr 5	10/96	Complete Both Medina and Health Hill used pre-existing committee's to fulfill this activity	
1 2 Complete needs assessment and develop a written technical assistance plan for each replication site through collaboration by project and site staff	Project Director / Project Coordinator / Site Coordinator/ Site Staff	Month 37-39 YR 4 49-51 YR 5	Medina 7/94 Health Hill 7/95 10/96	Complete	See copies of Medina and Health Hill Replication Plans
1 3 Implement a technical assistance plan at each site, including consultation, inservice workshops, and provision of resource materials in order for sites to implement the PPCS model	Project Director / Project Coordinator / Site Coordinator/ Site Staff	On-going YR 4 On-going YR 5	Medina 7/94 & On-going Health Hill 7/95 & On-going	Complete	See copies of Medina and Health Hill Replication Plans
1 4 Establish or refine a Quality Assurance Program and Committee to conduct quarterly reviews of participant's records	Project Director / Project Coordinator / Site Coordinator/ Site Staff	Month 39, 42, 45, 48 YR 4 Month 51, 54, 57, 60 YR 5	10/96	HLF has procedures in place. Medina has an established Quality Assurance Program. Health Hill did not request assistance with this activity	
1 5 Write and Implement policies and procedures at each site pertaining to PPCS program	Administrator of each Site/ Project Director	As needed YR 4 As needed YR 5	Medina ongoing - completed 7/19/96 Health Hill ongoing - completed 8/96	Complete	

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION I Program Implementation

GOALS 2 Infants and children considered for admission to the PPCS Replication Program will be those with complex health care needs from birth to eight years of age and their families

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2 1 All PPCS referrals will be processed through the Replication Site Coordinator and discussed with the Project Coordinator on a monthly basis	Site Coordinator/ Replication Staff/ Project Coordinator	Monthly YR 4 & 5	Medina 7/94 - On-going until 10/96	Complete Medina - PPCS assisted in refining referral process Health Hill - No new referrals They used existing involved families	Health Hill initially only agreed to replicate the PPCS training course
2 2 Site Coordinator will monitor intake meetings with families and discuss with Project Coordinator on a monthly basis Technical Assistance will be provided on an as needed basis by the Project Director and Coordinator	Project Director / Project Coordinator / Site Coordinator	On-going	Medina on-going until 10/96 Health Hill - N/A	Complete	Not part of technical assistance requested for Health Hill
2 3 Site Coordinator will monitor signature of parent/guardian consent forms, enrollment paperwork, and completion of initial study data This information will be copied and given to the Project Coordinator on a monthly basis	Site Coordinator/ Project Coordinator	Medina 7/94 & On-going Health Hill - N/A	Medina On-going until 10/96 Health Hill - N/A	Complete	Medina - Attempted twice to obtain consents Resulted in obtaining 4 consents Used the data of only those who gave consent

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION I Program Implementation

GOALS 3 An Individual Family Service Plan (IFSP) or IHP/IEP specific to the developmental and medical needs of the child and the goals identified by the family will be written with measurable goals and a description of the child's and family's strengths and performance level with respect to each goal at each site

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Site Coordinator will monitor the administration of child assessments and family interviews and discuss with the Project Coordinator on a monthly basis. Technical assistance will be provided on an as needed basis by the Project Director	Replication staff/ Site Coordinator/ Project Coordinator / Project Director	Month 37-48 YR 4 49-60 YR 5	Medina 7/94 & On-going until 10/96 Health Hill - N/A	Complete	This originally was not a part of the Health Hill replication plan, although HLF/PPCS did provide technical assistance in adaptation of child assessments and family interviews
3.2 Monitor the Individual Family Service Plan (IFSP), the Individual Educational Plan (IEP), and the Individual Service Plan (ISP) processes to ensure family participation and the incorporation of medical, nursing, educational, psychological needs of the child. The Project Director will be available for consultation	Replication Staff/ Site Coordinator/ Project Coordinator / Project Director	Month 37-48 YR 4 49-60 YR 5	Medina 7/94 & on-going until 10/96 Health Hill - N/A	Complete	Health Hill only agreed to replicate the PPCS training course

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION I Program Implementation

GOALS 4 Replication sites will provide access to and/or services and coordination to enable families to use community services through multiple service providers

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
4 1 Project Staff will provide consultation and technical assistance to replication sites in locating and coordinating medical, health, social, educational, dental, therapeutic, transportation and specialized respite care services desired by families.	Project Director / Project Coordinator / PPCS Staff	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/95 & On-going until 10/96	Complete	Documented in Medina and Health Hill replication plans
4 2 Assistance will be provided to Replication Staff and admitting agencies in transitioning families and children by the Project Director	Project Director / Replication Staff	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill - N/A	Complete	Health Hill only agreed to replicate the PPCS training course

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION I Program Implementation

GOALS 5 Modify technical assistance and consultation on basis of evaluation data

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
5.1 Assist Site Coordinator in evaluation the replication program as delineated in the Evaluation Plan and according to project timelines	Project Director / Site Coordinator	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/95 & On-going until 10/96	Complete	Medina - Evaluation plan in place, satisfaction data being collected Health Hill - Evaluation plan in place. Data collection is beginning in October of 1996.
5.2 Modify project methods accordingly	Project Director	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/94 & On-going until 10/96	Complete	

MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION II Training

GOALS 1 Provide comprehensive initial and on-going training to all PPCS Replication staff and families on family -centered coordination.

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1 1 Conduct Training Needs Assessment at each replication site	Project Director / Site Coordinator / Replication Staff	Month 37 - 39 Year 4 Month 49 - 51 Year 5	Medina 7/94 Health Hill 7/95	Complete	
1 2 Conduct orientation training with Site Coordinators, Replication Staff and Families to acquaint them with the philosophy, goals, services of the PPCS program	Project Director	Month 37 - 39 Year 4 Month 49 -51 Year 5	Medina 6/94 7/94 Health Hill 7/95 9/95	Complete	
1 3 Offer on-going Inservice training to Replication Staff, Site Coordinators, and Families that will foster growth and enhance skill levels (e g Improving communication skills to facilitate collaborative relationships, setting priorities, hands - on techniques, etc) and increase understanding and coping with the effects of childhood illness on a monthly basis	Project Director / Medical Training and Educational Support Staff	Month 37 - 48 Year 4 Month 49 - 60 Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/95 & On-going until 10/96	Complete	These activities are documented in the Medina and Health Hill Replication Plans
1 4 Determine training program effectiveness through pre/post measures, participant satisfaction, and QA reviews	Project Director / Project Coordinator/ Medical and Educational Support Staff / Site Coordinators	On-going Year 4 On-going Year 5	Medina 7/94 & On-going until 10/96 Health hill 7/95 & On-going until 10/96	Complete	Medina & Health Hill trainings were observed and feedback was given after each training

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION II Training

GOALS 2 Promote community development through offering inservice training to interested area agencies, schools, hospitals and professionals

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2 1 Provide technical assistance and consultation to Replication Staff and Site Coordinators on methods of developing their communities through team consultation and training efforts	Project Director	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill - N/A	Complete	Health Hill only agreed to replicate the PPCS training course
2 2 Assist Replication sites in planning and hosting at least one training workshop which focuses on families and children with complex medical needs	Project Director	Month 42 - 48 Year 4 Month 49 - 60 Year 5	6/96	Complete	Family Vision 96 - 6/4/96 The Family Vision Conference was hosted by the HLF/PPCS and both Medina and Health Hill sites presented workshops. Health Hill also had an exhibit booth.

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION II Training

GOALS 3 Recruit and train in-home and out-of-home respite providers and match them with appropriate families

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Provide technical assistance and consultation on recruitment and screening of specialized respite care providers	PPCS Staff - Recruiter	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/95 & On-going until 10/96	Complete	Specific activities documented in Medina and Health Hill Replication Plans
3.2 Provide training, technical assistance, and consultation on training content areas of the Specialized Respite Care Program through PPCS including: obtaining funding for respite, curriculum for licensed and non-licensed providers; documentation forms for training and assessment; the assessment process; monitoring providers; documentation of service provision forms; and the evaluation process and documentation	Project Director / Project Coordinator / PPCS staff - trainer	As needed Year 4 As needed Year 5	Medina 7/94 & On-going until 10/96 Health Hill 7/95 & On-going until 10/96	Complete	Specific activities documented in Medina and Health Hill Replication Plans

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MANAGEMENT PLAN YEAR I - YEAR III

FUNCTION III Administration and Management Procedures

GOALS 1 Determine program costs in order to establish staff/service costs and make certain that the program remains financially solvent

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1 1 Refine design of PPCS Program to be a cost-effective alternative to hospital, long-term care facility and in-home nursing care	Executive Director/ Associate Director/ Project Director/ Project Coordinator	Month 37 Year 4 Month 49 Year 5	10/96	Complete	
1 2 Write up yearly operational budget for the program	Executive Director/ Associate Director/ Financial Director/ Project Director/ Project Coordinator	Month 38 Year 4 Month 49 Year 5	Month 38 Month 49	Complete	
1 3 Approve allowable expenditures for the ongoing operation of the program	Executive Director/ Associate Director/ Project Director/ Project Coordinator	On-going Year 4 On-going Year 5	10/96	Complete	
1 4 Process necessary reimbursement information and do ongoing fiscal grant documentation and reporting	Financial Director/ Associate Director/ Project Director/ Project Coordinator	On-going Year 4 On-going Year 5	10/96	Complete	

MANAGEMENT PLAN YEAR I V- YEAR V

FUNCTION III Administration and Management Procedures

GOALS 2 Evaluate the timelines and effectiveness of the project administration and management

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.1 Maintain on-going records of adherence to timelines for completion of all project activities	Project Director/ Project Coordinator	On-going monthly update of management plan	10/96	Complete	
2.2 Conduct weekly meetings with project staff to review progress and make adjustments as needed	Project Director/Project Staff	On-going	10/96	Complete	
2.3 Summarize progress in quarterly reports for the Advisory Board and the Hattie Larlham Board of Trustees	Executive Director/ Associate Director/ Project Director/ Project Coordinator	Month 39,42,45,48, Year 4 Month 51,54,57,60 Year 5	10/96	Complete	
2.4 Summarize progress in annual reports for the Advisory Board and the Hattie Larlham Board of Trustees	Executive Director/ Associate Director/ Project Director/ Project Coordinator	Month 48 Year 4 Month 60 Year 5	10/96	Complete	

MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION IV Dissemination, Replication and Impact

GOALS 1. Disseminate information about the PPCS Project locally to universities, child training programs, hospitals, long-term care facilities, area agencies working with young children and other similar organizations within and outside of Ohio

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Develop and disseminate newsletter four times yearly to PPCS Program staff, families, area hospitals, agencies, schools and other interested individuals or programs	Project Director	Month 39,42,45,48 Year 4 Month 51,54,57,60 Year 5	10/96	Complete	Newsletter which includes training articles sent to respite providers and PPCS staff on a monthly basis
1.2 Prepare, print, and disseminate written information about the PPCS Program and services in the form of (a) a brochure, (b) fact sheet, (c) Model Handbook, (d) Parent Handbook, and (e) training materials/videos developed by the project	Project Director	Month 37 - 48 Year 4 Month 49 - 60 Year 5	10/96	Completed Brochure Fact Sheet PPCS Model Handbook PPCS Parent Handbook PPCS Training Book PPCS Video	
1.3 Present project design and transition methods at local, state, and national workshops and conferences such as DEC, TASH, Professional Association for the Care of Children's Health (ACCH)	Project Director	Month 39 - 44 Year 4 Month 51 - 60 Year 5	10/96	Complete	See list of dissemination activities
1.4 Preparation and submission of three articles for publication in journals which focus on infants and young children, such as Infants and Young Children and Children's Health Care	Project Director	Month 38 - 48 Year 4 Month 49 - 60 Year 5	10/96	One article has been published. Two more articles are ready to submit for publication	

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION IV Dissemination, Replication and Impact

GOALS 2 Disseminate PPCS Model and Parent Handbook for use by families and other agencies in and outside of Ohio					
ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2.1 Disseminate a Model and Parent Handbook to Replication Sites and other agencies within and outside Ohio	Project Director	Month 37 - 48 Year 4 Month 49 - 60 Year 5	10/96	Complete	Replication sites received sections at a time as they were finished throughout years 4 & 5. They received a final complete copy in 10/96

MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION V Evaluation and Research

GOALS 1. Evaluate the impact of the PPCS project on (a) hospital readmission data, (b) differences in economic and family stress levels, and (c) developmental progress between children served through the PPCS Program and replication sites

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
1.1 Refine and/or approve research studies analyze various program components such as (a) medical aspects, (b) child health and development, (c) family variables and (d) cost comparison studies	Project Director / Project Coordinator	On-going through Year 4 On-going through Year 5	10/96	Complete	Refinement and evaluation studies were completed at HLF. Refinement of the model took place at both replication sites. Health Hill has an evaluation plan in place and will begin in 10/96. Medina operating with existing county board plans.
1.2 Collate and interpret data to be used for reporting of research findings	Project Director / Project Coordinator	Month 42, 48 Year 4 Month 52, 60 Year 5	10/96	Complete	
1.3 Refine questionnaires used in analysis of Program Impact	Project Director / Project Coordinator	As needed Year 4 As needed Year 5	10/96	Complete	
1.4 Distribution of questionnaire (plus interview) to staff members and replication group to determine perceived benefits and impact for child and family	Project Director / Project Coordinator	On-going Month 42,48 Year 4 Month 54,60 Year 5	10/96	Complete	Preliminary findings indicated that too much paperwork is the reason for withdrawing or choosing not to participate in the study, therefore, evaluation paperwork became a part of department policy which improved data return and collection.
1.5 Distribution of questionnaire (plus interview) to staff members and replication group agencies/professionals (community impact) to determine perceived benefits and impact for the family and child	Project Director / Project Coordinator	On-going Month 42, 48 Year 4 Month 54, 60 Year 5	10/96	Complete	

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MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION V Evaluation and Research

GOALS 2 Evaluate the effectiveness of project management

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
2 1 Document the achievement of project goals and compliance to timetable	Project Director	Monthly Year 4 Monthly Year 5	10/96	Complete	See management plan
2 2 Compare actual expenditures for project with budget projections and modify as needed	Project Director/ Associate Director/Financial Director	Month 48 Year 4 Month 60 Year 5	10/96	Complete	

MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION V Evaluation and Research

GOALS 3 Evaluate financial viability and cost -effectiveness of the PPCS Program					
ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
3.1 Continue to document and compare health care expenditures for families whose children receive PPCS Program at the original site with health expenditures with those in the replication sites	Project Director / Project Coordinator	Month 48 Year 4 Month 60 Year 5	N/A		This was not negotiated in the replication contracts due to difficulty in retrieving this information from families

MANAGEMENT PLAN YEAR IV - YEAR V

FUNCTION V Evaluation and Research

GOALS 4 Evaluate the impact of the project where used in replication sites

ACTIVITIES	PERSON RESPONSIBLE	GRANT TIMELINE	COMPLETION DATE	PROGRESS TO DATE	COMMENTS
4.1 Evaluation process and instruments and procedures used to determine impact on children, families, and community service providers	Replication site staff / Outside Evaluator / Project Director / Project Coordinator	Month 48 Year 4 Month 60 Year 5	10/96	Complete	See PPCS replication accomplishments and the outside reviewers report

REPLICATION EVALUATION

OF

PERSONALIZED PEDIATRIC COORDINATED SERVICES (PPCS)*

*A GRANT AWARD TO THE HATTIE LARLHAM FOUNDATION, MANTUA, OHIO BY THE U.S. DEPARTMENT OF EDUCATION, OFFICE OF SPECIAL EDUCATION AND REHABILITATION (OSER) CF 024B

BY

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OUTSIDE CONSULTANT

ON

SEPTEMBER 30, 1996

RESPECTIVELY SUBMITTED,

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Consultant DT

INTRODUCTION

Purpose and Methodology

The purpose of this report is to describe the results of an independent program evaluation of the two year Replication Phase (1994 - 1996) of a grant award to the Hattie Larlham Foundation by the U.S. Department of Education, Office of Special Education and Rehabilitation (OSER) CF024B known as "Personalized Pediatric Coordinated Services" (PPCS).

Methods used to evaluate the replication phase of the project consisted of meetings and interviews with key personnel including project managers, coordinators and others at both original and replication sites as well as a review of relevant, selected documents, manuals, data, methods, policies and procedures with a focus on project goals, timeliness and processes.

Methods, scope and results of this evaluation are limited to those which could be realistically accomplished within the twenty-five (25) hour time frame contracted for review activities and report preparation by one outside consultant.

History of the Project

The five year PPCS Project began in 1991, is based upon a family-centered model of coordinated services for young children, age eight years or less, with chronic illnesses and disabilities including profound developmental disabilities.

Major project activities were geared toward validation and replication of the PPCS model at one original and two replication sites. Three important components of the model developed and replicated were:

1. Specialized Respite Services
2. Service Coordination and
3. Community Development

The first three years of the PPCS project were directed toward activities and clients identified at the original site with replication occurring at the two other sites during the fourth and fifth years. An independent review was completed at the end of Year III with favorable results and continued funds were granted for the two year replication phase. Project sites are briefly described next.

Project Sites

The original site for the PPCS project is located at the Hattie Larlham Foundation (HLF) in Mantua, Ohio. HLF is an integrated service agency dedicated to comfort, joy and achievement for children with profound disabilities. The Foundation was established in 1961, and employees over 450 staff serving more than 400 families who have children with profound disabilities throughout Northeast Ohio. Service options include residential care, integrated special needs daycare, community based respite care; foster care social work, service coordination and case management.

The Medina County Board of Mental Retardation and Developmental Disabilities (Medina) is located in Medina, Ohio and served as the initial replication site. This agency serves families and eligible residents of Medina County whose members are mentally retarded/developmentally disabled with programs for clients whose severity ranges from minimally to profoundly disabled. Programs include Children's Services focusing on early intervention, preschool and school activities, Center and Community Employment; Case Management such as Placement, Service Coordination, and Service Monitoring; Ancillary Rehabilitation Services; and Residential and Family Support designed to support persons in their choice of place of residence and provide resources to families designed to reduce/eliminate out of home placement.

Health Hill Hospital for Children (HHHC) is located in Cleveland, Ohio and served as the second replication site for only the Respite Training Component of the model. HHHC is a private non- profit pediatric subacute hospital, the only pediatric rehabilitation and specialty hospital in Ohio and one of only eighteen in the country. It operates a 52 bed inpatient facility and provides more than 7,000 outpatient visits annually. Most patients are accepted by referral from other acute care facilities and 85% of them are covered by Medicaid. Children with chronic illness and disabilities receive a comprehensive, coordinated family-centered program of services and education designed to maximize each child's potential for a life of health and functional independence.

Other Site Considerations

The original project was designed to replicate the model in five sites. However, upon recommendation of the review during the third year, the plan was altered to achieve a more realistic replication at two or three sites. Several possible sites were explored. One site, West Virginia-Southern Ohio, which represented several agencies serving chronically ill and disabled children, agreed to participate in replication; however, after five months, HLF dissolved the agreement due to complications arising from nurse practice regulations. No other suitable site was identified and the project sites consisted only of HLF, Medina and HHHC.

Implementation of the Model

During the initial three years of the FPCS project, HLF developed, field-tested and implemented a family-centered model of coordinated services for young children with chronic illness and disabilities. Specialized Respite Services, Service Coordination, and Community Development are the three major components of the model.

Training materials, parent and model handbooks, data collection instruments and forms, policies and procedures were instituted with modifications and refinements made as needed. At the end of the third year, the project was reviewed by a team of outside consultants. Additional modifications were made based upon based upon reviewer recommendations. Funding of the model was continued. HLF successfully located other funds to operate services at their facility during Years IV and V of the grant and were able to continue training and service delivery based upon the FPCS model.

Thus far, more than 200 families have been served by the HLF FPCS model and many others indirectly benefited by project dissemination. More than 200 respite providers have been trained as well by HLF.

In preparation for implementation of the replication phase of the project, formal agreements were finalized and signed for each site during Year III for Medina MRDD and Year IV for HHHC.

Key project staff at each site were identified. The Project Director, Site Coordinator (HLF) and other relevant personnel visited sites and oriented personnel to the FPCS model and its components. Needs assessments were completed for each site which identified the training, technical assistance and consultation needed from project staff. A plan was developed delineating time lines and processes for replication activities at each facility.

Policies, procedures and forms needed were reviewed with relevant staff at replication sites and FPCS project staff assisted as needed with development, revision, and implementation through a sharing of resources, training, support and technical assistance.

Replication formally began at the Medina site during the fourth year. Plans were made to replicate all three components of the model at this site although, in reality, their major focus has been on Specialized Respite Services and Service Coordination with some Community Development involvement. The HHHC replication site joined the project one year ago and agreed to replicate only the Respite Training Component of the model since their primary interest was in respite training for foster families.

Replication activities at these two sites are described next in terms of contributions and strengths of the project and project staff and problems and issues encountered in replication of the model components.

Contributions and Strengths of the Model

The most important contribution of the Respite Services component of the FPCS project has been the provision of services and training based on a family centered approach which matches respite providers to the family and trains providers until they are comfortable with their skills and their clients. This approach results in increased family comfort and satisfaction as well as improved satisfaction among respite providers. Recruitment and retention of providers who may plan careers in nursing or special education is an added plus. At the Median site, more than 50 families have been served and more than 40 providers trained. Although HHHC only recently implemented their second training group, average attendance at the first training course was 6 persons and attendance ranged form 5 to 16 for each session.

The FPCS project has increased awareness at all sites of respite care as needed and valued service. This increased awareness and experience with respite training and services has led to new market development at all sites as well.

Project staff at both replications sites emphasized the importance of the project for the development and future expansion of their respite services and training components. For example, one site is now considering whether to consolidate all training by using the FPCS training model department-wide.

Additionally, the FPCS model and staff were instrumental in supporting and assisting Medina in their negotiation and successful designation as a single intake site for referrals for the County MRDD and in the development of referral procedures used. This site also reports enhanced quality assurance activities resulting from the formation of a quality assurance advisory team and the adoption of the Home Visit and Family Satisfaction with Provider Services survey tools which they monitor for quality and follow up on complaints made.

The development of a model handbook, project video, training modules, a parent handbook and dissemination activities have contributed to a greater understanding of the special care needs of children with chronic illness and disabilities, particularly mental retardation and developmental disabilities. Numerous presentations at national, state and local events as well as the publication of the model handbook, at least two articles and the planned development of others in the area of clients rights, communication with families and training issues in home based respite care have aided in dissemination and community development throughout the project period.

Trained respite providers and service coordinators have impacted Community Development and Service Coordination through a more effective use of services and the inclusion of children in the community who otherwise may not have been served. Client needs were addressed through a process of Individualized Family Service Plan, Individualized Educational Plan, Individual Habilitation Care Plan and increased use of resources.

The Service Coordinator role serves as mediator between family and providers and improves family advocacy. One replication site reports that involvement in the project has placed them at the forefront of service coordination in the Ohio MRDD field because of their participation in the project as service coordination has become an increasing concern in community based care.

The Community Development component of the model aided in the dissemination of the unique family centered approach to respite services and service coordination. Both HLF and Medina staff served on county collaboratives for early intervention with children with chronic illness and disabilities and complex medical needs. Families were educated through conferences, training and seminars such as the Family Vision-96 Conference presented by HLF. Staff from both replication sites participated and family involvement was stressed.

Project staff operating in the community have provided expertise in developmental disabilities and special care needs to families and community providers in more traditionally focused agencies as well and assisted them to explore alternate funding sources.

Helpfulness of Project Staff to Replication

Project Site Coordinators at both replication sites report satisfaction and a high level of support from FPCS Project Director and Staff in their willingness to assist each agency to develop training, coordinate activities and emphasize a focus on the model now that a collaborative relationship has been established.

Coordinators at all sites report improved networking with important social agencies, identification of additional funding for services and assistance with recruitment and training of families, instructors and providers.

Each facility plans to continue its Respite Training and Services. HLF is not applying for outreach funding because of the complexities of funding regulations in multiple geographic areas. However, other funding sources are being explored.

For example, HLF project staff prepared a letter of support on behalf of HHHC on a grant application for respite training and services from a private foundation. HHHC has been awarded $176,000 dollars to continue to develop respite services and credit their association with the FPCS model as crucial to this award. HLF staff also contributed to HHHC's knowledge of funding sources available through the local MRDD Board which has resulted in a closer affiliation with the Board. Because of the new grant, other community organizations will assist HHHC to locate candidates for respite as well.

It is expected additional contributions of the project and its staff will continue once final research and evaluation data analysis and report preparation are completed and results are shared with the professional community through individual staff and agency efforts.

Problems and Issues Encountered in Replication

Despite the many valuable contributions made by the project and its staff, several problems occurred during the replication phase which seriously impact the evaluation and research contributions of the project.

Perhaps the most serious issue stems from the inadequacy of data sharing from replication sites. For example, data shared from one site includes only some family satisfaction with provider data and some family demographic data of the client population eligible for services. From the other site, only provider satisfaction with training data has been shared. No family data is available from this site for analysis. Neither site has shared cost comparison/effectiveness data with FPCS.

Consequently, FPCS ability to make comparisons and estimate average replication impacts is seriously impaired.

No single factor may explain data collection and/or sharing problems. However, some possible explanations gleaned from interviews with project staff include inadequate contract specificity, inadequate understanding or differing views on activities needed to support replication efforts, turnover of key staff at the replication sites, professional turf issues, and internal agency events which distracted from a focus on project activities. For example, at one site, project implementation was adversely affected by a ten week employee strike, multiple personnel changes and a physical move to a new facility resulting in some misplaced or lost data which had apparently been collected but not retrieved.

In fact in most instances of delayed timelines and missing data, agency internal events and decisions are a likely explanation. It appears likely much of the data were collected but not shared in a timely fashion.

Underlying these problems are tensions engendered by a changing and very competitive health environment which required a much longer period of time than anticipated to establish a collaborative working relationship with replication sites resulting in delays in meeting timelines for forms modifications, training materials and agreement on model modifications, particularly in the area of medication administration and delegable nursing tasks training for respite providers at one site. This issue remains under consideration within that agency as to future direction but will need to be addressed as respite services expand and are fully in place.

Other modifications to the model were made at each site to accommodate unique circumstances, funding, facility and client population differences. For example, one site required a model which included a team-oriented approach addressing issues of aging, longevity and Alzheimer's Disease while another site focuses on younger children with complex medical needs who are less developmentally disabled than either of the other two sites.

Also impacting problems faced when examining evaluation results are the constraints imposed by funding sources in which respite services are determined by pre-established numbers of funded hours allowed rather than by severity of client illness or need.

Respite services and training are at a break-even point because no funds are available for overhead or supervision of providers. Thus, there must be continual efforts directed toward finding funds for these components of the program which has distracted replication implementation efforts. Changing in funding of service coordination also occurred.

Also complicating the determination of cost effectiveness are issues stemming from billing practices and third party reimbursement. Measuring impact of providers and service coordination is influenced by the multiple payor sources and providers who may be caring for the same client. Many families were reluctant to share financial data and complete cost forms for the project as well.

Project staff plan to address cost effectiveness by sampling twenty (20) cases where data are available for respite services and service coordination to evaluate the cost to HLF to provide these services.

Additionally, HLF does have five years of rich data collected on their involvement with the project and clients served which will yield substantial insights into model effectiveness and impacts on family, community and providers. Data comparisons can be made between those served under eight years of age and those over eight not in the project study group but served by the Community Services Department at HLF.

Certainly insights gained and materials developed and disseminated are indicative of an active, ongoing project which while making substantial contributions was not quantitatively replicated as planned in the model design. However, triangulation of the data using both quantitative and qualitative methods do allow for additional analysis and evidence of model effectiveness.

It is possible several problems described in this section may have been addressed differently or alleviated if the Year IV review of replication progress by an outside consultant had been completed as prescribed by project design. There have been four different project directors during the five year study. Each change of directors reportedly affected project focus and continuity to some degree.

Fortunately several key staff have been with the project for some years and were able to retain core activities during transitions of leadership. Personnel at both sites agreed that current relations with project management and staff are good. Collaboration and focus has improved during the past few months. All sites report substantial benefits to their facility and services offered stemming from involvement with the project and the PPCS model. The PPCS project officially ends September 30, 1996. Final data analysis and report preparations are being completed by project staff at this point.

RECOMMENDATIONS

Recommendations stemming from this consultant review of replication of the PPCS project conducted at the end of the fifth year include:

1. PPCS project staff should complete data analysis which can be appropriately utilized to reflect replications where possible and prepare a report of findings in a timely fashion.

2. Dissemination of findings should continue at professional meetings and in journal publications.

3. A core model of replication should be clearly defined and fully operationalized prior to initiation of any future research based on this model.

4. Future studies based on the model should more specifically address data collection, data sharing, methods and responsibilities in contractual agreements.

5. In replication studies based on this model, all sites should review delegable nursing tasks regulations as they relate to respite providers and design training programs, policies, procedures and practices to assure compliance with nurse practice regulations in their geographic areas.

6. Although the PPCS model offers a valuable and unique family-centered approach to service delivery and training it does not lend itself to replication in multiple geographic sites at this time due to the complexities of funding and other regulatory barriers. (Such barriers could probably be overcome provided adequate funding was included for service delivery, particularly for overhead, supervision and training of respite providers).